

**SURVEY OF ADULT CONSUMERS OF DEVELOPMENTAL SERVICES**  
**STATE OF VERMONT 2001 REPORT**

Report of Satisfaction or Positive Responses on  
Residence, Employment, Day Activities  
&  
Services

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Susan L. Culbert, Ph.D., Sara N. Burchard, Ph.D., & David Kelley

Consumer Survey Project  
Burlington, Vermont

## **PURPOSE**

This survey was conducted as part of the State of Vermont's Quality Assurance procedures. The structured interview obtained consumer information on satisfaction with residential living, work and/or day activities, community services, case management, and satisfaction with other valued outcomes such as, social support, neighbors, leisure activities, degree of independence, opportunities for growth and change, and information on self-advocacy, and self-determination. Susan Culbert, Ph.D., and Sara Burchard, Ph.D., developed the interview and field-tested it extensively. The format and questions were reviewed and approved by a variety of stakeholders which included family members, service providers, consumers, and representatives from the State Division of Developmental Services. A number of questions have been added to the original survey in order to include the survey results in the national Core Indicators Project, a project including 22 states that provides a 'report card' on services to adults receiving developmental services. Additional questions have been included for the State Division of Developmental Services to provide additional information on consumer knowledge of services. A copy of the surveys can be found in Appendix A.

This report contains the results of the consumer survey for 410 adult consumers of developmental services from six agencies in the State of Vermont during the summer of 2001. The six agencies include Champlain Vocational Services (CVS), Community Associates (CA), Howard Community Services (HCS), Northeast Kingdom Human Services (NKHS), Specialized Community Care (SCC), and United Counseling Services (UCS). Those agencies were chosen to provide a regional representation of consumers throughout Vermont and a representation of size of developmental services agencies in Vermont. Some survey results from earlier years (1995-1999) are included for comparison. The results are reported showing aggregated consumer responses to individual questions, and questions grouped by content area. Comparisons are made across types of residence and types of work and day activity on consumer satisfaction.

## **PROJECT STAFF**

In order to obtain the consumer's own point of view and to eliminate possible bias or influence, the State Division of Developmental Services contracted with psychologists affiliated with the University of Vermont to act as an independent group to coordinate and implement the collection of consumer satisfaction interviews on a statewide basis. Susan Culbert, Ph.D., and Sara Burchard, Ph.D., the project coordinators, hired and trained eight field interviewers to complete the consumer interviews. The interviewers included three psychology graduate students, two consumers of developmental disabilities services, and three advanced undergraduates.

## **PROCEDURE**

The procedure for selecting survey participants was changed from prior years. Interviews conducted from 1995-1999 were statewide by random selection of a certain percentage of consumers within each agency over the course of the four years (there were no interviews during 1996). At the request of the agency directors, the sampling was changed for 2001 from statewide, random sampling to sampling based upon size of agency and regional representation. In addition, all interviews will be conducted over the course of three years instead of four years. Such sampling will allow agency participation to be completed in one year rather than over four years for all but the largest agency (at their request, random sampling will be completed over the course of three years).

Interviews were scheduled through each of the six participating agencies for all consumers who were deemed by the agency as able to participate in a verbal or pictorial interview. For five of the agencies, every consumer was expected to participate in the survey by the provision of demographic information and, when feasible, by direct consumer interviews. At HCS, the agency scheduled interviews from a random sample provided them by Survey Project staff. The sample was 20% of their consumers

Throughout the summer and early fall of 2001, Project staff went to agency sites to interview the consumer participants. The interview questions were read to each consumer individually and the answers were recorded. Not all survey questions were applicable for every consumer, and not all consumers answered all of the questions in their interviews.

## **PARTICIPANTS**

There were 410 survey participants this year. For all of the participants, demographic information was collected. For 253 of the participants, direct interviews were also conducted. Table 1 on page 4 shows the type of interview completed. There were 201 consumers that were able to participate in the full self-report interview and 52 that were able to participate in the pictures-only interview. The interviews took an average of 32 minutes to complete during the summer of 2001.

**Table 1 - Types of Interviews Conducted (n=410)**

<b>Type of Interview</b>	<b>Number Completed</b>
Full Interview	201
Picture Only Interview	52
Interview attempted unable to complete	6
No Show	20
Refused after meeting interviewer	4
Person's Choice not to participate	10
Person out of town	4
Person incapacitated	1
Agency Decision (Communication Issue)	97
Agency Scheduling Oversight	3
Guardian Decision	2
Other or Unknown	10
Total	410

Each agency had consumers who could not or did not participate in the direct consumer interviews. For five of the six agencies, interviewers expected to collect demographic information on all consumers of that agency either while at the agency for the direct consumer interviews or later by phone call. At HCS, demographic and service information was requested for a random sample comprising 20% of their consumers. Agency staff was asked to use the consumers' records when providing demographic and service information. Table 2 on page 5 has a breakdown by agency of the reasons why 127 consumers were scheduled for demographic interviews only. In addition to the 127 accounted for below, there were 30 other consumers that did not complete the interview: six were met for interviews but did not have the communication skills necessary to complete the interview, 4 refused to participate after meeting briefly with an interviewer, and 20 did not show up for their scheduled interview. For these 30 consumers, only demographic information was collected. Table 2 shows the reasons that 127 individuals were not scheduled for any interview. Appendix E shows the numbers of individuals and their level of participation.

**Table 2 - Reasons that Consumers were not scheduled by Agency**

	Person's choice	Person out of town	Person incapacitated	Agency decision (Communication Issue)	Agency scheduling oversight	Guardian's decision	Reason unknown	Other	Total
CVS	0	0	0	11	0	0	0	0	11
CA	8	0	1	10	0	0	0	4	23
HCS	1	0	0	45	0	0	0	0	46
NKHS	1	1	0	13	3	2	1	4	25
SCC	0	0	0	1	0	0	0	0	1
UCS	0	3	0	17	0	0	0	1	21
Total	10	4	1	97	3	2	1	9	127

Table 3 below shows the living situations for the 410 participants. Table 4 on page 6 shows the developmental disability as noted in their record for the 410 participants. It is interesting to note the high number of consumers with mild or moderate cognitive challenges who were not interviewed. While there were various reasons given by agency personnel for why those consumers did not participate, 70 of those reasons fell into two categories. Twenty consumers were scheduled to be interviewed but did not show up for their interviews and 50 consumers were not scheduled as agency personnel indicated that the individuals did not have sufficient ability to communicate.

**Table 3 - Number of Consumers by Residential Type**

Residential Type	2001 Interviews	2001 Demographics Only	2001 ALL
ICF / Nursing	5	3	8
Group Home	14	8	22
Staffed Residence	7	6	13
DH/Family	65	57	122
DH/Roommate	14	6	20
DH/Neighbor	1	0	1
Family Home	74	59	133
Semi-independent	59	13	72
RCH	9	1	10
Other/Unknown	5	4	9
Total	253	157	410

ICF/Nursing = Intermediate Care Facilities / Nursing Facilities

DH = Developmental Home types were divided into Developmental Homes with Families (DH/Family), Developmental Homes with Paid Roommates (DH/Roommate), and Developmental Homes with Neighbor Support (DH/Neighbor).

RCH = Residential Care Homes

**Table 4 – Developmental Disability Label**

	2001 Sample (n=253)	2001 Demographic only (n=157)	2001 Demographic Information All (n=410)
Mild	188	59	247
Moderate	45	44	89
Severe	7	33	40
Profound	1	6	7
Unspecified	7	9	16
Asperger's Syndrome	1	n/a	1
Autism	1	n/a	1
Missing Data	3	6	9

Table 5 below shows the number of participants who experience additional challenges. A majority of consumers in the demographic only group had additional challenges and overall 232 of the 410 consumers (57%) had one or more additional challenges.

**Table 5 - Number of Individuals with a Particular Challenge**

	2001 Sample (n=253)	2001 Demographic only (n=157)	2001 Demographic Information All (n=410)
Cerebral Palsy	22	27	49
Brain Injury	19	42	61
Chemical Dependence	2	n/a	2
Mental Illness	59	33	92
Medically Fragile	13	24	37
Physically Challenged (other than mobility)	7	20	27
Hearing	14	21	35
Other	40	28	68
Non-Ambulatory	13	25	38
Uses Cane, Walker, or Wheelchair	36	44	80

The 410 consumers who participated were between the ages of 18 and 87 years with a median age of 39 years. There were 186 females and 220 males identified. The gender of four consumers was not identified on the forms, most likely due to an interviewer oversight.

About one quarter (114 consumers) of the participants were independent of a guardian. There were 187 people who had private guardians, and 102 who had Guardianship Services. There were 7 with this data missing.

Demographic data collected included the locations of the consumer's residence. In 2001, there were 84 consumers that lived in a town or village, 120 that lived within walking distance of a town or village, and 200 that lived in rural areas. Data were missing for six consumers.

Other demographic data collected included information about court ordered restrictions (e.g., Act 248, probation, etc.), annual physicals, and family involvement. There were 14 individuals in this sample that had court ordered restrictions. There were 353 that had seen a doctor within the last year. There were 355 who had family involved in their lives. Some participants either did not know the whereabouts of family members or their family members had died. Other participants had family members that either did not want to be involved in their lives or had court orders restricting their contact with family.

Table 6 below displays the numbers of individuals receiving the different types of services available in Vermont. There were 333 people who received home and community based waiver funded services. There were 67 consumers who "self manage" their services with of whom 47 consumers provided direct consumer interview information. Table 7 shows the numbers of consumers that have been involved in hiring their case managers and/or support staff. Only 14 of the 67 consumers who were managing their own services were involved in the hiring of support staff.

**Table 6 - Number of Individuals Receiving Services**

	2001 Survey Group (n=253)	2001 Demographic only Group (n=157)	2001 Totals
Case Management	231	140	371
Home Support	114	85	199
Employment Support	128	56	184
Community Support	129	94	223
Family Respite	112	95	207
Clinical Intervention	93	51	144
Crisis Services	128	93	221
Transportation	98	80	178
Other	7	1	8

**Table 7 – Self-Management and Hiring Support Staff**

Self-manage services	Not Involved in Hiring	Involved in Hiring	Totals
yes, all services	16	5	21
yes, some services	35	9	44
No	308	19	327
Total	359	33	392

Of the total number of participants, 186 had some form of paid work. Table 8 below displays a breakdown of the type of work consumers were doing and the number of hours consumers were working each week. On average, consumers that were working were working approximately 14 hours a week. The two largest categories of employment were independent competitive employment (follow along only)(50% of those working) and individually supported employment (40% of those working).

**Table 8 - Type and Number of Hours of Employment**

	Competitive Employment	Supported Employment	Enclave/ Work Crew	Sheltered Employment	Total/ Mean
<i>Number of People (Demographic Only)</i>	27	28	0	2	57
<i>Mean Number of Hours per Week</i>	18.5	8.7	0	17	13.4
<i>Number of People (Full Interview)</i>	67	51	7	4	129
<i>Mean Number of Hours per Week</i>	15.4	11	14.6	14.8	13.7
<i>Number of People (Total)</i>	94	79	7	6	186
<i>Mean # of Hours (Total)</i>	16.1	10.2	14.6	15.5	13.7

Of the 410 participants, 235 (or 57%) had a daytime activities . Table 9 below shows a breakdown of the types of daytime support received and the average hours per week that consumers were receiving such support. On average, consumers received 15 hours of daytime support per week. The most common type of support was individualized versus group support. Note that in table 9, some people have more than one service and therefore are counted more than once.

**Table 9 – Type and Number of Hours for  
Daytime Activities**

	Individualized & Companion- ship	Group	PASARR	Total/ Mean
Number of People (Survey Group)	109	41	3	153
Mean Number of Hours	15	10	7	14
Number of People (Demographic Group)	83	23	2	108
Mean Number of Hours	18	10	9	16
Number of People (Total)	192	64	5	261
Mean # of Hours (Total)	16.2	10	7.4	15.3

PASARR is specialized community supports to people who are in nursing facilities

## **RESULTS**

The remainder of this report will provide information regarding the results of the 253 direct consumer interviews. At times, comparisons will be made between 2001 data and 1995-1999 data which represents all adult consumers in the state who were receiving developmental services and who were willing and able to be interviewed.

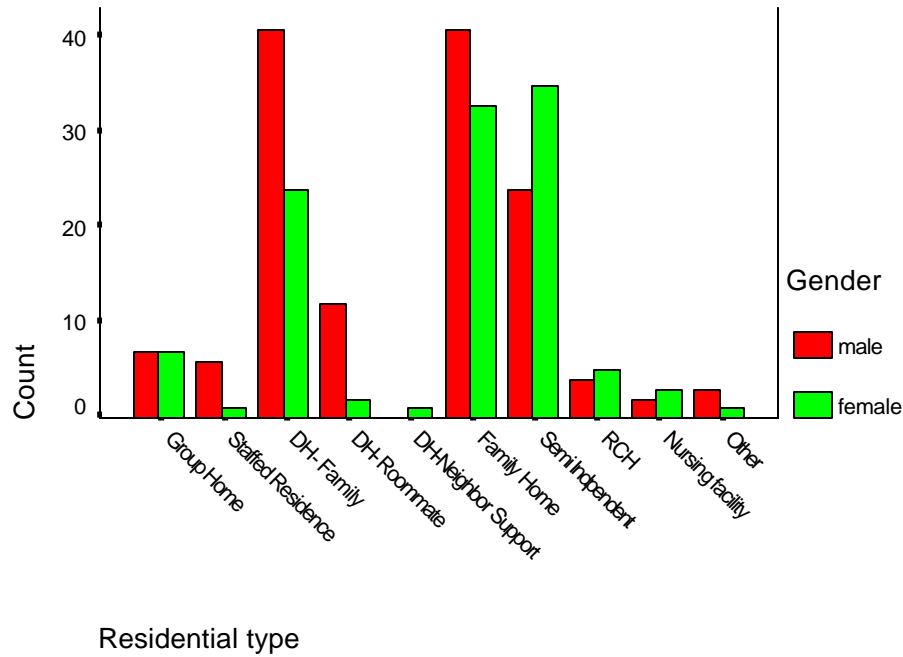
Table 10 on page 10 shows the demographics and residential living situation of this sample of 253 consumers compared to the entire statewide sample collected over four years from 1995 to 1999. As shown in Table 10, the 253 consumers who participated in 2001 did not differ from the statewide consumer sample in age, gender, living situation, or number of identified challenges in addition to their identified level of developmental disability. There was a difference between this 2001 regional sample and the entire state sample in level of developmental challenge. The 2001 sample included more individuals who were labeled mildly mentally challenged in their records than was the case from 1995-1999. However, there was no association (correlation) between level of challenge in this sample and any outcome measures in the survey. Figures 1 and 2 on page 11 show gender and level of challenge by living situation.

**Table 10 -Comparing Sample Characteristics from the 2001 Sample to Data  
Collected in the 1990's**

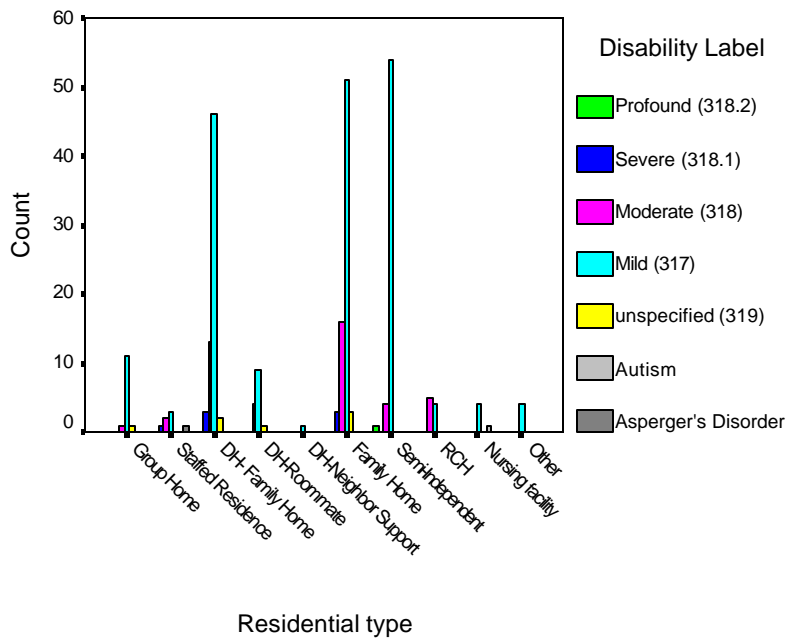
	2001 Sample (n=253)	1995-1999 Sample (N=876)	Significance
<b>Gender</b>			
Male	140	464	$\chi^2=.442, df=1, p=.506,$ ns
Female	113	412	
<b>Age</b>			
Mean	40	40	$t=-.327, df=1112,$ $p=.743, ns$
Median	39	37	
Minimum	18	17	
Maximum	87	98	
<b>Developmental Disability Label</b>			
Mild MR	188	597	$\chi^2=3.95, df=1, p<.05$
Moderate MR	45	206	
Severe MR	7	49	
Unspecified MR	1	7	
Asperger's Syndrome	1	n/a	
Autism	1	n/a	
<b>Living Situation</b>			
ICF / Nursing	5	16	$\chi^2=6.98, df=6, p=.327,$ ns
Group Home	14	53	
Staffed Residence	7	26	
DH/Family	65	n/a	
DH/Roommate	14	n/a	
DH/Neighbor	1	n/a	
DH/Unidentified	n/a	333	
Family Home	74	220	
Semi-independent	59	189	
RCH	9	33	
Other	5	6	
<i>Total</i>	253	876	
<b>Number of Additional Challenges</b>			
	2001 Sample (n=253)	1995-1999 Sample <sup>1</sup> (n=178)	
No Additional Challenges	164	96	$t= 1.3, p=.149, ns$
One Additional Challenge	72	72	
Two Additional Challenges	14	10	
Three or more Additional Challenges	3	0	

<sup>1</sup> Additional challenges were not collected in 1995-1997.

**Figure 1 -Gender and Living Situation of 253 consumers**



**Figure 2- Living Situation by Disability Level for 253 Consumers**



The results from all 253 consumers to the 160 individual survey questions about residence, autonomy, social support, activities, work, and services are found in Appendix B. The following are selected findings from the questions.

### Residential

- 202 people were happy where they were living, 27 people wanted to live somewhere else, 16 were in between.
- 168 people felt that where they lived was a good place to live, 8 people felt they lived in a bad place, and 22 were in between
- 132 people could name a better place to live, 3 people said there was a better place, but could not name it, and 52 people named a better place to live.
- 33 people who lived with unpaid staff felt they had a say about whom they lived with, and 62 people felt they had no say about whom they live with (Questions 13 and 17).
- 38 people who live alone liked living by themselves and 6 people did not.
- 196 people were happy about their free time spent at home, 13 were sad, and 34 were in-between.
- 120 of 194 (62% of respondents) felt that there were fun things to do at home, 39 people were bored, and 35 people were in between.
- 50 of 180 (28% of respondents) wanted more chores at home, 124 people had enough chores, and 6 people were in between.

### Autonomy

- 94 of 186 (51% of respondents) reported not having a choice in where they lived, 92 people felt they did have a say.
- 125 of 197 (63% of respondents) said that they decided what they eat, 61 people said that someone else picked what they eat, but they liked it, 11 people said someone else picked what they eat and they did not like it
- 67 of 95 (71% of respondents) reported that someone else makes the rules for living at their house; 28 people reported making their own rules.
- 66 of 83 people felt the rules at their homes were good rules, 6 people felt the rules were bad, and 11 people were in between.

- 155 of 188 people reported that they were allowed to invite friends and family over when they wanted to, 20 people could not, and 13 people could sometimes invite people over.
- 70 of 125 (56% of respondents) said they make decisions about visits, and 55 people reported someone else makes decisions.
- 125 of 170 (74% of respondents) said they have privacy when their friends visit, 38 people reported not being able to be alone with friends, and 7 could sometimes be alone.
- 67 of 175 (38% of respondents) said that someone had talked to them about dating, 108 people had not talked with anyone about dating.
- 117 of 173 (68% of respondents) said they did not need to know more about dating, but 56 people wanted to know more about dating.
- 104 people hold their own money, and 77 people do not hold their own money.
- 151 people decide how they spend their money and 32 people reported that someone else decides.
- 27 of 187 (14% of respondents) reported that people enter their home without asking.
- 29 people reported that people enter their bedrooms without asking.
- 56 of 189 people said that they could not go out whenever they want, they had to wait for someone to take them.
- 95 of 155 people said they could stay home alone if they want to, 48 had to go when people in their home went out, and 12 people could sometimes be left alone.
- 25 of 63 people without a pet would like to have a pet.

### Neighbors/Neighborhood

- 10 of 168 people said the neighbors were not friendly, and 14 people were in between.
- 138 people were happy with their neighborhoods, 28 people wanted to live in a different neighborhoods that they named, and 6 people wanted to live a different neighborhood but did not name it.
- 143 people felt safe in their neighborhood, and 27 people felt unsafe

## Work

- 129 people did some form of paid work: 67 had independent competitive jobs with follow-along support only, 51 had individually supported jobs, and 11 individuals had other work arrangements. 114 people had no paid work.
- 18 people that were not working indicated that they wanted a job and 39 people did not want a paid job, other people did not answer that question.
- Work hours ranged from 1 to 40 hours per week (mean = 13.7 hrs./wk, median = 14 hrs./wk)
- 110 of 116 (95% of respondents) reported that the place where they worked was a good place to work.
- 8 were unhappy with their jobs and 7 people were in between.
- 43 of 118 (36% of respondents) would like to work more hours
- 101 of 116 (87% of respondents) indicated that people at work treat them with respect.
- 34 of 64 people (53% of respondents) said they did not choose their job coach, 17 people chose with assistance, and 17 people made the choice unassisted.

## Daytime Activities

- 136 people interviewed participated in daytime activities: 41 people received group day activity support, 109 people received individual day activity support, and 3 people who lived in nursing facilities received daytime services.. Seventeen received group and individual services.
- 88 of 93 people (95% of respondents) reported they were happy with their daytime activities programs.
- 32 of 91 (35% of respondents) reported wanting more hours of daytime activities
- 45 people engaged in volunteer work activities on a regular basis which involved from 1 to 30 hours per week (median = 3 hrs./wk.)
- 12 of 34 people wanted more hours to volunteer
- 41 of 43 people reported they were happy with their volunteer activities

### Friends/Social Support

- 136 people indicated that they had plenty of friends, 45 indicated they were lonely, and 3 people were in between.
- 173 people indicated that if they need help there is someone to help them and 6 people said there was no one to help them.
- 130 of 179 people (73% of respondents) said they had a best friend and 49 people did not.
- 148 people reported that they were happy on most days, 35 people reported that they were sad most days, and 5 people were in between.
- 112 people saw their family members as much as they want, and 46 people hardly ever see their families.

### Community Services

- 193 of 231 (84% of respondents) indicated that they were happy with their agency, 15 people said they were sad, and 23 people were in between.
- 194 people were happy with their case managers, 7 people were sad about their case managers, and 18 people were in between.
- 99 people said someone else chose their case managers, 30 chose with assistance, and 37 people chose unassisted.
- 121 people could see their case managers when they wanted, 23 people could not see their case managers when they wanted, and 26 people could sometimes see their case manager when they wanted.
- 32 people said it was hard to reach their case managers, 31 people were in-between, and 104 people said it was easy to reach their case manager.
- 115 of 144 (80% of respondents) were happy with their guardians
- 63 of 94 (67% of respondents) indicated that their guardians let them make some decisions for themselves.
- 145 of 161 people (90% of respondents) felt listened to at their ISA meetings, 6 people did not feel listened to, and 10 people felt listen to at times.

- 137 of 165 (83% of respondents) did not know how much money their agency had budgeted to spend on their services. 11 people said they knew the amount but could not give a figure and 17 people said they knew the amount, and were able to give a figure.
- 35 of 171 (20% of respondents) were aware of their agency complaint process, 136 people were not aware of the complaint process

### Activities

- Many people participated in the activities they wanted to.
- Of those people 23% wanted to do the activities more often.
- Slightly over one third of the people not participating in a particular activity would like to.
- Some of the activities people wanted to do more were: going out to eat, going to the church or synagogue, playing sports, and visiting family and friends

### Opportunities

- 109 people indicated they had never attended a self-advocacy meeting, conference, or event, 95 because of a lack of interest, and 53 people had attended a self-advocacy meeting for the social opportunity it presented.
- 79 people would like to know more about self-advocacy/determination and 86 felt they knew enough about self-advocacy.
- 132 of 165 (80% of respondents) saw themselves as self-advocates.
- 104 people indicated that they get to learn new things/skills and 67 said they do not ever get to learn new things/skills

## **SUBSCALE RESULTS**

The interview questions were organized by their content into subscales (groups of related questions combined). The subscale scores are reported as percent satisfaction with Residence, Neighborhood, Work, Daytime Activities, Social Support, Community Services, Guardian, and Activities. The subscale of Autonomy is presented as the average percent of positive responses, reflecting independence and choice. The questions that make up these subscales are shown in Appendix C. A copy of the 2001 survey is found in Appendix A and responses to each question of the 160 questions are found in Appendix B.

The subscale results, percent positive and satisfied responses by content area, are shown in Table 10 that follows. The results for all 253 interview participants are in the right hand column of that table.

### **Scale Comparisons between Residence Type, Type of Work, Activity and Guardianship**

The results of the Vermont consumer survey for 253 consumers are presented by Type of Residence, Type of Employment, Type of Day Activity, and Type of Guardian Status. These results are presented by percent satisfaction or percent of positive responses for subscales of satisfaction. Where satisfaction differences were found between types of residence, employment, or day activities or legal (guardian) status on a subscale of satisfaction, then the individual questions in that scale were further examined for differences.

### **Satisfaction and Autonomy and Type of Residence**

To determine whether there were any differences in satisfaction between consumers in Developmental Homes, Family Homes, and Semi-Independent living situations, statistical analyses were performed on satisfaction subscales. Since the numbers of consumers in the other living situations were relatively small they were not included in the statistical analyses. However, their responses are included in the average satisfaction for all persons. Table 11 on page 18 shows satisfaction subscales by residential type and for the entire sample.

To first verify that all types of Developmental Homes are equivalent throughout the state based on 2001 surveys, a comparison of Developmental Homes in family homes and Developmental Homes with paid roommates was conducted. In this sample, 72 Consumers lived in Developmental Home situations with a family while 15 consumers lived with a paid roommate (there were no consumers with neighbor support to analyze). The analyses indicated a significant difference between Developmental Home roommate situation and Developmental Home Family situation on the neighborhood scale. People living with roommates were more satisfied with their neighbors. All other subscale comparisons between the two types of developmental homes were not significant. Since

the neighborhood has not been a focus of the current research, the two types of Developmental Home were combined for the following comparisons. For more information on comparisons between Developmental Home types based on data obtained during the 2001 interviews see Appendix D.

The primary analyses used were one-way analyses of variance (ANOVAs) and post hoc t-tests. In general, there must be a large difference in mean scores and little variability among scores within a group for a statistically significant difference. There may be instances where the percentages seem quite different but are not statistically different due to a small sample size, a large range or variability between scores within a group, or a combination of the two. The overall subscale differences by residential type are shown in the following table (Table 11).

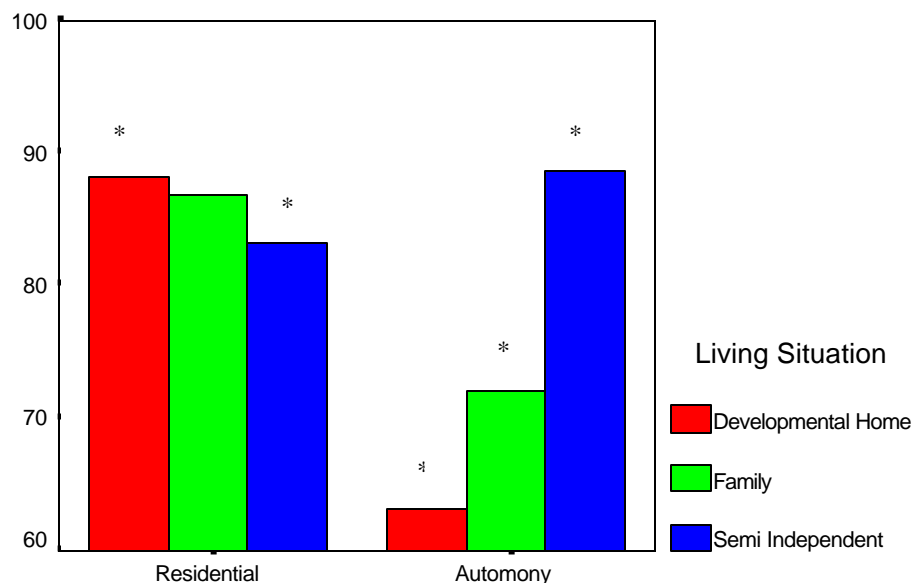
**Table 11: Subscales and Total Satisfaction By Residential Type**  
(2001)

Reported as Average Percent Satisfied or Percent Positive					
Subscale	Family Home	Semi - Independent Living	All DH	Mean for Three types of residence	Means for all individuals surveyed
<i>Number People</i>	74	59	80	213	253
*Residential	87	83 <sup>a</sup>	89 <sup>b</sup>	87	86
* Autonomy	72 <sup>b</sup>	89 <sup>a</sup>	63 <sup>c</sup>	75	75
Neighborhood	86	84	88	86	85
Work	87	88	87	88	87
Day Program	87	95	91	90	89
Social Support	78	80	83	81	81
Activities	76	76	71	74	74
Guardian	74	81	77	76	76
* Services	79	78	85	81	81
Health	87	90	93	90	90

\* indicates a significant difference for the given subscale ( $p < .05$ ). Superscripts (a, b, c) indicate which groups differ. Groups with the same superscript do not differ from each other and groups with no superscripts do not differ from any other group.

Figure3 - Average Satisfaction

By Residential Type (n=213)



*\*Indicates a significant effect at  $p < .05$*

- Persons living in a Developmental Home were more satisfied with their residence than people living Semi-Independently.
- Persons living in Developmental Homes were not different than individuals living with family members in Residential Satisfaction.
- Persons in Semi-Independent living situations were significantly more autonomous than persons living in Developmental Home or Family Home living situations.

The individual questions which make up the subscales where significant differences between living situations were found were also examined for differences between residence types using chi-square analyses. These analyses compare the responses between consumers living in Developmental Homes, Family Homes, and Semi-Independent living situations. The consumers' original responses, however, are provided in Tables 12 and 13 beginning on page 20. The other living arrangements had too few persons to be included in these comparisons.

The subscale for service satisfaction did reach significance for the general ANOVA, but Post-hoc tests did not show any difference for the three residential settings. In addition, Chi-Squared analysis on individual questions showed a difference on only one question (question 142). This question showed that more individuals in family homes and in developmental homes could name someone to help them change services or support in comparison to those living semi-independently.

### **Residential Satisfaction by Residence Type**

There was a significant difference in Residential satisfaction (See Figure 3). Persons in Semi-Independent living situations generally reported less satisfaction with their residence than persons living in Developmental Home living situations. Analyses of individual questions on the scale showed that there were significant differences in responses between the types of residence. However, for there to be a significant Residence satisfaction scale difference between living settings, there is also a trend across the scale that supports that difference. (See Appendix A and B)

The four questions that are different between settings are shown below. (Qs. 1, 29, 55 & 66):

- Persons in Developmental Homes were more satisfied with their living situation than persons living in Semi-independent living situations.

The questions that differed by setting are presented below with superscripts to indicate which settings were different from the others.

**Table 12: Residential Satisfaction by Residence Type**

1. Are you happy living there or would you like to live somewhere else?

	Family Home	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
SOMEWHERE ELSE	7	13	2
IN BETWEEN	5	4	3
HAPPY	57	42	74

29. Show me how you feel about the jobs/chores you do around your house.

	Family Home <sup>a</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
HAPPY	41	41	64
IN BETWEEN	16	8	7
SAD	2	7	2

55. Do people go into your house and take your things?

	Family Home	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
NO	48	49	54
YES, FOLLOW UP NOT ANSWERED	2	0	0
YES FOLLOW UP ANSWERED	2	8	1

66. Do you want to have a pet? (Persons without a pet)

	Family Home	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
NO	12	19	2
YES	2	7	6

### **Residential Autonomy by Residence Type**

There were many differences in Autonomy between the three primary living situations. Persons in Semi-Independent living situations generally reported more autonomy than persons living in Family Home, or Developmental Home living situations, however, this was not always the case (See Figure 3). Each question in the Autonomy scale was tested with chi square to determine if there were differences in choice between the three residential settings. There were significant differences in 22 out of 30 questions on that subscale.

- Persons in Semi-Independent living situations were more autonomous than persons in Developmental Homes or Family living situations or both in 22 of 30 autonomy/choice questions.
- In 4 cases, persons living with their Families were more autonomous than persons living in Developmental Homes: having friends over whenever you want; being by yourself when you want; talking on the phone in private; and being able to stay at home if you don't want to go out with others. (Questions # 35, 37, 40, and 59).

The questions that differed by setting are presented below with superscripts to indicate which settings were different from the others.

**Table 13: Residential Autonomy by Residence Type**

3. Did you have any say in choosing that place to live?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home
YES	18	34	28
NO	33	20	28

7. Who decides (picks) what you eat?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
SELF	31	51	27
OTHER, LIKE IT	19	7	25
OTHERS, DON'T LIKE IT	5	0	5

8. Who decides (picks) what you wear?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
SELF	48	57	47
OTHER, LIKE IT	9	0	8
OTHERS, DON'T LIKE IT	0	0	2

13. Did you have any say about who lives there with you?

	Developmental Home	Semi-independent
YES	8	6
NO	37	2

22. Do you choose or pick the things you do for fun?

	Family Home	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
SOMEONE ELSE CHOOSES	2	1	1
YES, WITH HELP	8	2	15
YES, WITHOUT HELP	45	54	39

26. Are you told what jobs to do or do you get to pick the jobs/chores you want to do?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
TOLD	15	2	16
IN BETWEEN	6	2	6
PICK	26	51	31

30. Who makes the rules for living here?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
SELF	4	15	5
OTHERS	19	3	34

31. What happens if you don't like a rule? Can you change a rule?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
NOTHING	10	0	16
COMPROMISE	11	5	19

33. What if you want to drink a beer or some wine in your house? Is there no drinking allowed there (at home) or can you have a beer or wine there (at home) if you want?

	Family Home <sup>a</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
Have a Drink	32	39	47
Not Allowed	11	12	3

35. Can you invite your friends or your family over to your house whenever you want to?

	Family Home <sup>b</sup>	Semi-independent <sup>b</sup>	Developmental Home <sup>a</sup>
YES	44	52	38
SOMETIMES	3	2	4
NO	4	1	12

36. Who decides when you can have friends/family over to visit?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
SELF	7	35	12
OTHERS	20	2	30

37. Can you be by yourself as much as you want to? (Do you have enough time to yourself, enough private time?)

	Family Home <sup>b</sup>	Semi-independent <sup>b</sup>	Developmental Home <sup>a</sup>
YES	49	52	39
SOMETIMES	1	2	4
NO	5	3	14

38. Does anyone ever open your mail without asking you first?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home
YES	8	2	2
NO	42	52	46

39. Can you use the telephone when you want to?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
YES	42	56	44
SOMETIMES	3	0	5
NO	6	0	6

40. Can you talk on the phone in private or do other people listen in?

	Family Home <sup>b</sup>	Semi-independent <sup>b</sup>	Developmental Home <sup>a</sup>
LISTEN	5	2	12
SOMETIMES	1	2	6
PRIVATE	41	50	34

41. When you have friends over, can you be alone with them, or does someone have to be with you?

	Family Home <sup>b</sup>	Semi-independent <sup>b</sup>	Developmental Home <sup>a</sup>
HAVE PRIVACY	35	47	24
SOMETIMES	0	2	2
NOT ALONE	9	5	20

48. Can you have your own money whenever you want it or do you have to ask someone for your money?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
HAVE	27	36	24
ASK	23	17	32

57. Can you go out whenever you want to or do you have to wait for someone to take you?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
WHEN WANT	31	49	34
WAIT	21	7	21

58. Do you have to wait for someone to bring you home or can you come home when you want to?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
WHEN WANT	36	50	43
WAIT	16	6	11

59. When people in your house go somewhere, do you have to go or can you stay home alone if you want to?

	Family Home <sup>b</sup>	Semi-independent <sup>b</sup>	Developmental Home <sup>a</sup>
CAN STAY ALONE	41	19	22
SOMETIMES	6	2	3
HAVE TO GO	8	3	30

60. Do you have a key to your house?

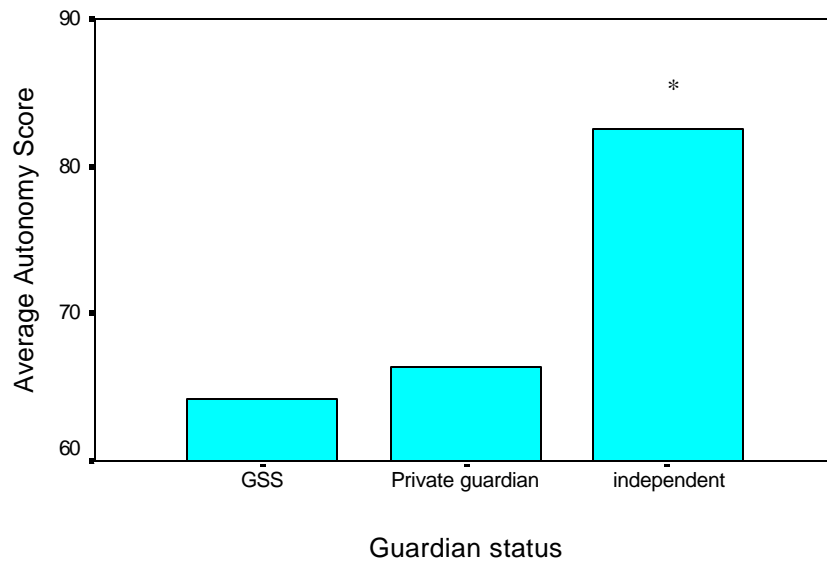
	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
NO	20	1	35
YES	34	55	19

61. Do you use your key whenever you want to or do you have to ask to use your key?

	Family Home <sup>b</sup>	Semi-independent <sup>a</sup>	Developmental Home <sup>b</sup>
FREELY	29	55	17
ASK	4	0	3

*Superscripts (a, b, c) indicate which groups differ. Groups with the same superscript do not differ from each other and groups with no superscripts do not differ from any other group.*

Figure 4 - Autonomy Scores by  
Guardian Type (n=199)



\* Autonomy questions cannot be scored for the pictures only questionnaire. Therefore 52 persons did not contribute to these data.

- Individuals with state appointed guardians (Guardianship Services Specialists or GSS) and private guardians did not differ on any subscale.
- People who do not have a guardian were more autonomous than those that had assigned guardianship. These individuals were also more likely to live in semi-independent living situations. Table 14 displays Guardian status by living situation.

**Table 14 – Type of Guardian by Living Situation**

Residential type	GSS	Private guardian	Independent	Total
Group Home	2	6	2	10
Staffed Residence	3	1	1	5
DH- Family Home	21	16	9	46
DH-Professional Roommate	4	4	2	10
DH-Neighbor Support	0	0	1	1
Family Home	2	29	26	57
Semi Independent	8	5	45	58
Residential care home	5	1	0	6
Nursing facility	0	0	3	3
Other	0	1	2	3
Total	45	63	91	199

### **Satisfaction and Type of Employment**

The results of the interview questions which make up the Work Satisfaction subscale are presented in Table 15 broken down by type of employment. To determine whether there were any real differences in satisfaction a t-test was performed between persons with Independent Competitive Employment (follow along only) and persons with Individual Supported Employment. There were too few persons working in the other employment situations to be examined, however, their responses are included in the total for all persons.

- There was no difference in Work satisfaction between those with Independent Competitive Jobs and those with Individual Supported Jobs.

**Table 15: Work Satisfaction By  
Type of Employment**  
Reported as Average Percent Satisfied

	Competitive Employment	Supported Employment	Enclave/ Work Crew	Sheltered Employment	Total/ Mean
<i>Number of People (Full Interview)</i>	67	51	7	4	129
Work Satisfaction (97-99)	84	82	79	77	81
Work Satisfaction (2001)	81	79	80	79	81

- Work Satisfaction is computed for years 1997, 1998, and 1999

- Consumers worked between 1 and 40 hours a week (mean = 13.7, median= 14 hours/week).
- Responses in 97-99 and 2001 for follow along support only were categorized as competitive work and supported employment were taken from individuals who receive ongoing assistance at work

### **Satisfaction and Type of Day Activities**

The results of the interview questions on Day Activity satisfaction are presented in Table 16 as the average percent satisfaction by type of day activity of a group.

**Table 16: Day Activity Satisfaction By  
Type of Day Activities**

Reported as Average Percent Satisfied

	Individualized & Companion- ship	Group	PASARR	Total/ Mean
Number of People (Survey Group)	109	41	3	153
Day Program Satisfaction (2001)	82	81	N/A	82

- NA represents cases where 3 or fewer consumers responded. These percentages are not included to maintain consumer anonymity

- Consumers were involved with day activities between 4 and 40 hours a week (mean = 14 hours/ week).

- PASARR is specialized community supports to people who are in nursing facilities.

-

- 136 people that received daytime activities, 17 people received both individual and group activities.

**APPENDIX A**  
**SATISFACTION SCALE SUPPLEMENT**



Consumer ID# \_\_\_\_\_ Agency ID# \_\_\_\_\_ (Location: \_\_\_\_\_ )  
Agency #2 ID# \_\_\_\_\_ (Location: \_\_\_\_\_ )

DATE of Interview: \_\_\_\_\_

Interviewer: \_\_\_\_\_ 2nd Interviewer: \_\_\_\_\_

If person was NOT scheduled for interview, check primary reason for why:

- ☐ Person's choice – declined opportunity for interview
- ☐ Person out of town
- ☐ Person incapacitated
- ☐ Agency decision – person has insufficient ability to reliably communicate to interview
- ☐ Agency scheduling oversight
- ☐ Guardian's decision
- ☐ Reason unknown
- ☐ Other (please specify): \_\_\_\_\_

GENDER: Male \_\_\_\_\_ Female: \_\_\_\_\_

DOB: \_\_\_\_\_ AGE: \_\_\_\_\_

RACE (check one): {OPTIONAL}

- ☐ American Indian/ Eskimo/ Aleut
- ☐ Asian/ Pacific Islander
- ☐ Black
- ☐ White
- ☐ Mixed Race
- ☐ Other/ Unknown

ETHNICITY (check one): {OPTIONAL}

- ☐ Hispanic
- ☐ Non-Hispanic

LEGAL Status: G.S.S. \_\_\_\_\_ Private Guardian \_\_\_\_\_ Independent \_\_\_\_\_

Average Annual Income (including SS, SSI, VA Benefits, work earnings, etc.):

\_\_\_\_\_ < \$8,000/yr. \_\_\_\_\_ \$8,000-11,000/Yr. \_\_\_\_\_ > \$11,000.

Does the person have a payee or someone who manages his/her money? Yes \_\_\_\_\_ No \_\_\_\_\_

MARITAL Status:

- ☐ Never Married
- ☐ Live-in partner
- ☐ Married now
- ☐ Married in past, single now

Does this person have any court-ordered restrictions (i.e., probation, parole, furlough, Act 248)?

- ☐ Yes; please list \_\_\_\_\_
- ☐ No

Does the person have any family that is involved in his/her life? ☐ Yes ☐ No

If NO, please check why not:

- ☐ Family gone/ no longer alive/ unknown
- ☐ Family's choice not to be in touch
- ☐ Court-ordered restrictions
- ☐ Other: \_\_\_\_\_

Has the person had a physical exam? ☐ Yes ☐ No

If YES, please check when:

- ☐ Within the past year
- ☐ Over 1 year ago

How is this person currently labeled in his/her records?

- Mild MR (317)
- Moderate MR (318.0)
- Severe MR (318.1)
- Profound MR (318.2)
- Unspecified MR (319)

And/or

- Autistic Disorder
- Asperger's Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder
- PDD, NOS

Challenges other than MR? (Check all that apply.)

- ☐ cerebral palsy
- ☐ brain injury/ neurological problems
- ☐ chemical dependency
- ☐ mental illness/ psychiatric diagnosis (other than PDD or MR)
- ☐ medically fragile
- ☐ physically challenged other than mobility
- ☐ hard of hearing/ deaf
- ☐ Seizures
- ☐ other (please specify) \_\_\_\_\_

Primary language:

- ☐ Speaks English
- ☐ Other primary language (please specify): \_\_\_\_\_

Does this person have adequate, reliable speech, which is understood by others (strangers) and allows himself/herself full expression? ☐ Yes ☐ No

If NO, what other means of communication does the person use?

- ☐ Spoken – understood by familiar listeners only
- ☐ Gestures/ body language
- ☐ Eye gaze
- ☐ Sign language or finger spelling
- ☐ Communication board/ book
- ☐ Electronic communication device
- ☐ Facilitated communication
- ☐ Other (please specify): \_\_\_\_\_

Mobility:

- ☐ Walks (ambulatory)
- ☐ Non-ambulatory

Does this person use assistive devices, such as a cane, walker or wheelchair?

- ☐ Yes
- ☐ No

Does this person require mobility assistance of another person?

- ☐ No, or almost never
- ☐ Occasionally needs help of another person
- ☐ Always requires help of another person

Vision:

- ☐ Sees well, with or without corrective lenses
- ☐ Vision problems limit activities, such as reading or travel
- ☐ Limited or no vision (legally blind)

Behavioral Challenges:

Self-Injury: Does this person ever cause injury to him/herself, for example by hitting self, biting, banging head, scratching or puncturing skin?

- ☐ No ☐ Yes
- If yes, about how often does this behavior occur?*
- ☐ less than once/month
- ☐ once/month
- ☐ 1-3 times/month
- ☐ 1-6 times/week
- ☐ 1-10 times/day
- ☐ one or more times/ hour

Disruptive Behavior: Does this person ever interfere with the activities of others, for example, by starting fights, laughing or crying without reason, yelling or screaming?

☐ No ☐ Yes

*If yes, about how often does this behavior occur?*

☐ less than once/month

☐ once/month

☐ 1-3 times/month

☐ 1-6 times/week

☐ 1-10 times/day

☐ one or more times/ hour

Uncooperative Behavior: Does this person ever engage in "uncooperative" behavior, for example, breaking rules or laws, cheating, acting defiant, or stealing?

☐ No ☐ Yes

*If yes, about how often does this behavior occur?*

☐ less than once/month

☐ once/month

☐ 1-3 times/month

☐ 1-6 times/week

☐ 1-10 times/day

☐ one or more times/ hour

### **Paid Services - Provider/Agency #1**

What supports does the person receive from service provider? (Indicate if a different agency provides support)

☐ Service Coordination/ Case Management

☐ Home Supports

☐ Employment Supports

☐ Community Supports

☐ Family Respite

☐ Clinical Intervention

☐ Crisis Services

☐ Transportation

☐ Other (please specify): \_\_\_\_\_

### **Paid Services - Provider/Agency #2**

☐ Service Coordination/ Case Management

☐ Home Supports

☐ Employment Supports

☐ Community Supports

☐ Family Respite

☐ Clinical Intervention

☐ Crisis Services

☐ Transportation

## Residential

What amount of residential support does s/he receive? (Check one of the four categories below.)

- A) 24-hour on-site support and/or supervision (i.e., people living with, or being available in his/her home during any hours that s/he is home)
- B) daily on-site support (i.e., for a limited number of hours-per-day; not round-the-clock)
- C) less frequent than daily support
- D) on-call only
- E) none

How might this living arrangement best be categorized?

- A) Intermediate Care Facility (ICF) - medical support
- B) group home
- C) staffed apartment
- D) developmental home (family care home)
- E) developmental home (professional roommate)
- F) developmental home (neighbor support)
- G) parents' or family member's home
- H) supervised living (living semi-independently)
- I) residential care home (community care home)
- J) nursing facility
- K) other (please specify)

Who own or leases the place where this person lives?

- A) Person rents home (name is on the lease)
- B) Person owns home (name is on the title)
- C) Family, guardian, or friend
- D) Individual/ family with whom the person lives
- E) Provider agency/ affiliate
- F) State or County agency (not mental health)
- G) Don't know
- H) Other (please specify) \_\_\_\_\_

Primary household composition:

- A) lives alone
- B) spouse/ domestic partner
- C) spouse/ domestic partner and minor child(ren)
- D) minor child(ren)
- E) biological/ adoptive parent(s)
- F) other relative(s)
- G) non-related individual(s)

Location of Residence:

- A) Residence is physically remote; not within walking distance to town or to public transportation.
- B) Residence located within walking distance to town/city (within 1/2 mile).
- C) Residence centrally located within city, town, or village center (within block or so of downtown).

How many people live in this household?

\_\_\_ With Developmental Disabilities (including consumer) receiving DS services

\_\_\_ Without Developmental Disabilities

How many different places has this person lived within the past year? (Count one for present home.) \_\_\_

How many moves are with the same provider? \_\_\_

### Non-Residential Activities

Please answer the following questions about this person's major activities outside of the home.

(Note: For most people, this would be their job or daytime program.)

Does the person participate in an unpaid day program on a regular basis?

No \_\_\_ Got to item #8. If "yes", check all that apply.

A) receives group day activity support

B) receives individual day activity support

C) companionship

D) other, please specify in detail: \_\_\_\_\_

What kinds of things do they do?

	Group	Individual	Companionship	Other
Hours/week				

Does this person perform paid work on a regular basis?

No \_\_\_ Go to item #9. If "yes", check the item below that best describes that work.

A) independent work (follow-along support only)

B) individual supported work

C) enclave or work crew

D) sheltered workshop

E) other work (please specify) \_\_\_\_\_

What kinds of things do they do?

Does this person do volunteer work on a fairly regular basis? Y / N

What kinds of things do they do?

For those work/volunteer activities that he/she does outside the home, fill in the chart below.

Leave blank those questions that do not apply.

a. How much does he/she work or spend time volunteering?

DO NOT include travel time.

	Paid Work	Volunteer Work
Hours/week		

Additional Services

Does this person receive Home and Community Based Waiver Services?

☐ Yes

☐ No

☐ Don't know

Does this person self-manage his/her services?

☐ Yes, all services

☐ Yes, some services

☐ No

Does this person hire their case manager?

☐ Yes

☐ No

Support staff (day)?

☐ Yes, all

☐ Yes, some

☐ No

Additional Information to Assist Interviewer

Service Plan: What is the annual service plan called in your organization - by what term would this person best know this document? (To assist interviewer)

Please list below first names only of live-in roommates/household members (to assist interviewer with interview): Indicate the name and the role of each person listed (i.e., housemate, home provider, spouse/partner, parent, sibling, spouse or child of care-provider, etc.).

First Name

Role

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Please list below first names only of regular staff members with whom the interviewee has contact (to assist the interviewer with the interview). Indicate the name and the staff role (i.e., job coach (JC); case manager (CM); residence staff (RS); Day Program (DP); guardian (GSS); etc.).

First Name

Role

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ID# \_\_\_\_\_  
Agency \_\_\_\_\_  
Date \_\_\_\_\_  
Int. \_\_\_\_\_  
Time \_\_\_\_\_

### SELF-PERCEIVED SATISFACTION SCALE



#### A. RESIDENTIAL

Where do you live? How do you like living there?

1. \_\_\_ Are you happy living there or would you like to live somewhere else?  
HAPPY=2; IN-BETWEEN=1; SOMEWHERE ELSE=0
2. \_\_\_ Is that a bad place to live or a good place to live? GOOD=2; IN-BETWEEN=1; BAD=0
3. \_\_\_ Did you have any say in choosing that place to live?  
YES=2; NO=0
4. \_\_\_ Can you think of a better place to live?  
NO=2;  
(If "YES," ask next two questions before scoring.)  
Where would that be?

Why would you like to live there?

IF BOTH FOLLOW-UP QUESTIONS ARE ANSWERED, SCORE=0; IF NOT  
SCORE=1.

5. \_\_\_ Is the food there pretty bad or do you like the food there?  
LIKE=2; IN-BETWEEN=1; DISLIKE=0
6. \_\_\_ Show me how you feel about the food at your house. (Show pictures of faces and describe each one.) HAPPY=2; IN-BETWEEN=1; SAD=0
7. \_\_\_ Who decides (picks) what you eat?  
SELF=2  
(If "OTHER", Ask "Do you have to eat things you don't like?")  
NO=1; YES=0

8. \_\_\_ Who decides (picks) what you wear?

SELF=2

(If "OTHER", Ask "Do you like what you wear?")

YES=1; NO=0

9. \_\_\_ Do you choose the times you do things each day, like when to get up, when to eat dinner, when to do laundry...? (Do you decide when you watch TV, when to go to bed?)

(If "YES", *Did someone help you with this choice?*)

YES, WITHOUT HELP=2; YES, WITH HELP=1,

NO, SOMONE ELSE CHOOSES=0

IF PERSON LIVES ALONE, GO TO NUMBER 19.

#### PEOPLE THEY LIVE WITH:

Who do you live with there? (Include as many as 6 names of people who live in the household.

Add names of those not given that live there. Write names in chart below.)

(Repeat questions 10-12 for every person listed alternating the order of nice/mean for question

#11. Use chart below.)

Names	10. Do you like living with___? YES=2 SOMETIMES=1 NO=0	11. Is___mean to you or is___nice to you? (alternate wording) NICE=2; IN-BETWEEN=1; MEAN=0	12. Show me how you feel about___. HAPPY=2; IN-BETWEEN=1; SAD=0

13. \_\_\_ (*Ask this question if not living with own family*)

Did you have any say about who lives there with you? NO=0, GO TO #14.

(If "YES", Ask, Who did you choose to live with you?).

IF FOLLOW-UP QUESTION IS ANSWERED, SCORE=2. IF NOT, SCORE=1.

#### STAFF/SUPPORT PEOPLE:

Who are the staff or support people who work there? (List first names of regular/residential staff. This section is for residential staff only. Make sure you are NOT asking about day activities staff, work staff, etc.)

(Repeat questions 14-16 for every person listed alternating the order of forced choice options for question #14. Use chart below.)

Names	14. Do you like or dislike ____? (alternate wording) LIKE=2 IN-BETWEEN=1 DISLIKE=0	15. Is ____ nice to you and polite? YES=2; SOMETIMES=1 NO=0	16. Show me how you feel about ____. HAPPY=2 IN-BETWEEN=1 SAD=0

17. \_\_\_ Did you have any choice in hiring (did you pick) who works at your house?  
NO=0;  
(If “YES”, Ask, “Who did you pick?”).

IF FOLLOW-UP QUESTION IS ANSWERED, SCORE=2. IF NOT, SCORE=1.

18. \_\_\_ Have you had a lot of different people support you there?  
NO=2  
(If “YES”, Ask “Is that a problem for you?”)  
NO=1; YES=0

COMPLETE ITEMS 19-21 IF PERSON LIVES ALONE.

19. \_\_\_ Do you like living by yourself? YES=2; NO=0

20. \_\_\_ Would you like to have someone live with you? NO=2 (then ask question 21)  
(If “YES”, Ask, “Who would you like to live with you? Why?”).

IF BOTH FOLLOW-UP QUESTIONS ARE ANSWERED, SCORE 0; IF NOT, SCORE 1

21. \_\_\_ Show me how you feel about living alone. (Show picture of faces.)  
HAPPY=2; IN-BETWEEN=1; SAD=0

THINGS TO DO:

What do you do for fun when you are at home? (Try to elicit a couple of responses.)

22. \_\_\_ Do you choose or pick the things you do for fun? ? Examples: Whether to take a walk, play a game, watch TV, select what’s on TV, etc Y/N (If Yes, Do you choose how you spend your weekends or time off?; If No, Who chooses the activities you do

(If "YES", Did someone help you with this choice?.)  
YES, WITHOUT HELP=2; YES WITH HELP=1;  
NO, SOMEONE ELSE CHOOSES=0

23. \_\_\_ Do you have enough to do when you're at home or do you sit around with nothing to do?  
ENOUGH=2; IN-BETWEEN=1; NOTHING=0

24. \_\_\_ Are you bored when you are at home, or is it fun to be home?  
FUN=2; IN-BETWEEN=1; BORED=0

25. \_\_\_ Show me how you feel about how you spend your free time at home. (Show pictures of faces.)  
HAPPY=2; IN-BETWEEN=1; SAD=0

#### **JOBS/CHORES:**

What are some of the chores/jobs you do at home? (Try to elicit a couple of responses, such as making the bed, doing dishes, setting the table, doing laundry, etc.)

26. \_\_\_ Are you told what jobs to do or do you get to pick the jobs/chores you want to do?  
PICK=2; IN-BETWEEN=1; TOLD=0

27. \_\_\_ Do you have to work too hard there (at home)?  
NO=2; SOMETIMES=1; YES=0

28. \_\_\_ Would you like to have more jobs/chores to do?  
NO=2; SOMETIMES=1; YES=0

29. \_\_\_ Show me how you feel about the jobs/chores you do around your house. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0

**RULES:**

What are the rules for living in that house? (Give examples only if necessary: Can you go to bed whenever you want? Can you watch TV whenever you want to? Can you smoke in the house?)

DO NOT INCLUDE LANDLORD RULES IN THE SCORING OF THIS SECTION.

(If "NO RULES", skip to #33 and then ask #35)

(If consumer does not know what rules are skip section except questions 33, 35, & 36.)

30. \_\_\_ Who makes the rules for living there?

SELF=2; OTHER=0

31. \_\_\_ Are the rules for living there good rules or are they bad rules?

GOOD=2; IN-BETWEEN=1; BAD=0

32. \_\_\_ What happens if you don't like a rule? Can you change a rule (like when you have to go to bed, etc.)? COMPROMISE=2; NOTHING=0

33. \_\_\_ What if you want to drink a beer or some wine in your house? Is there no drinking allowed there (at home) or can you have a beer or wine there (at home) if you want? HAVE DRINK=2; NOT ALLOWED=0; MEDICAL REASON/NOT OF LEGAL AGE=30

34. \_\_\_ Show me what you think about the rules at your house. (Show pictures of faces.)

HAPPY=2; IN-BETWEEN=1; SAD=0

35. \_\_\_ Can you invite your friends or family over to your house whenever you want to?

YES=2; SOMETIMES=1; NO=0 (If "sometimes," query further about who can/cannot visit.)

36. \_\_\_ Who decides when you can have friends/family over to visit?

SELF=2; OTHER=0

**PRIVACY and DATING:**

37. \_\_\_ Can you be by yourself as much as you want to? (Do you have enough time to yourself, enough private time?) YES=2; IN-BETWEEN=1; NO=0

38. \_\_\_ Do you ever get mail? If YES, Follow up:

Does anyone ever open your mail without asking you first? NO=2; YES=0

39. \_\_\_ Can you use the telephone when you want to? YES=2; SOMETIMES=1; NO=0

40. \_\_\_ Can you talk on the phone in private or do other people listen in?

PRIVATE=2; SOMETIMES=1; LISTEN=0

41. \_\_ When you have friends over, can you be alone with them, or does someone have to be with you?  
HAVE PRIVACY=2; SOMETIMES=1; NOT ALONE=0

42. \_\_ Has anyone ever talked to you about dating? (Having a boyfriend/girlfriend?)  
YES=2; NO=0

43. \_\_ Do you need to know more about dating? (Having a boyfriend/girlfriend?)  
NO=2; YES=0

Do you have a boy/girl friend? What is (his/her) first name? (If not or married/living with significant other, go on to #48.)

44. \_\_ Can you have \_\_ over to visit whenever you want? YES=2; NO=0

45. \_\_ Can \_\_ stay overnight at your house if you want, or is \_\_ not allowed to stay overnight?  
ALLOWED=2; SOMETIMES=1; NOT ALLOWED=0

46. \_\_ Do other people have to be with you when \_\_ is at your house, or can you be alone at your house with \_\_ if you want? ALONE=2; SOMETIMES=1; OTHER PEOPLE=0

47. \_\_ Can you spend time at \_\_'s house whenever you want or are you not allowed to go over to her/his house? YES=2; SOMETIMES=1; NOT ALLOWED=0

#### MONEY:

Let's talk about money. Who has your money? Does someone help you with your money?

48. \_\_ Can you have your own money whenever you want it or do you have to ask someone for your money? HAVE=2; ASK=0

49. \_\_ Show me how you feel about (self or other) having your money. (Show pictures of faces.)  
HAPPY=2; IN-BETWEEN=1; SAD=0

50. \_\_ Can you buy the things you want to buy or does someone else decide how you spend your money? SELF=2; SOMEONE ELSE=0

51. \_\_ Do people steal (take) your money? NO=2; YES=0

SAFETY:

52. \_\_\_ Do people in your house take your things or do they leave your stuff alone?  
LEAVE ALONE=2; TAKE=0

53. \_\_\_ Do people go into your house without asking?  
NO=2; YES=0

54. \_\_\_ Does anyone go into your bedroom without asking? NO=2; SOMETIMES=1; YES=0

55. \_\_\_ Do people go into your house and take your things? NO=2; (IF YES, ASK FOLLOW-UP)  
What kind of things do they take?

IF FOLLOW-UP IS ANSWERED, SCORE=0; IF NOT, SCORE=1.

56. \_\_\_ Do you feel safe in your home or do you feel afraid (scared) in your home?  
SAFE=2; IN-BETWEEN=1; AFRAID=0  
If person does not feel safe in their house, Ask "Why not?"

\* If person is "Afraid" for a reason that indicates they are in immediate danger or risk of serious harm SEE PROTOCOL.

COMING AND GOING:

Do you like to go out? (Go downtown, to the neighbors, to the stores, to someone else/s house?)  
Where do you like to go? REFER TO PICTURES IF NECESSARY

57. \_\_\_ Can you go out whenever you want to or do you have to wait for someone to take you?  
WHEN WANT=2; WAIT=0 (If "WAIT", try to determine whether the person  
*can go when they want and need a ride or if they must wait until it is*  
*"convenient" for someone else.)* How come you have to wait?

58. \_\_\_ Do you have to wait for someone to bring you home or can you go home when you  
want to? WHEN WANT=2; WAIT=0 (If "WAIT", try to determine whether the  
*person can go when they want and need a ride or if they must wait until it is*  
*"convenient" for someone else.)* How come you have to wait?

59. \_\_\_ When people in your house go somewhere, do you have to go or can you stay home alone  
if you want to? STAY ALONE=2; SOMETIMES=1; GO=0

60. \_\_\_ Do you have a key to your house? YES=2; NO=0 (If "NO," go to next section)

61. \_\_\_ Do you use your key whenever you want to or do you have to ask to use your key?  
FREELY=2; ASK=0

ACCESS/ TRANSPORTATION:

62. \_\_\_ When you want to go somewhere, do you have a way to get there?  
YES=2; SOMETIMES=1; NO=0.

63. \_\_\_ Are there places that you need to go to that you can't get to? (Such as to the doctor, the  
service agency, to go shopping, to the pharmacy, etc.) NO=2; YES=0

64. \_\_\_Are the places where you go for services or support easy to get to? YES=2; NO=0  
(e.g. to the doctor, the service agency, to go shopping, to the pharmacy, etc.)

PETS:

Are there any pets at your house? Y/N (If "YES," what kind? Then ask #65 and skip #66 & #67)  
(If "NO," skip #65 and ask #66 & #67)

65. \_\_\_Do you like having a pet? IF YES, SCORE=2; IF NO, SCORE=0; IN-BETWEEN=1

66. \_\_\_Do you want to have a pet? What kind of pet? NO=2; YES=0 (If, "YES", ask #67. If, "NO", skip #67.)

67. \_\_\_Can you have a pet at your house if you want to or are no pets allowed? YES=2; NO=0

Is there anything else that you want to tell me about where you live that we haven't already talked about; such as, things you like?

Things you don't like?

Things you want changed or fixed?

## **B. NEIGHBORHOOD**

Do you know any of the neighbors? If yes, can you tell me their first names? (List)

68. \_\_\_Are the neighbors friendly toward you? YES=2; SOMETIMES=1; NO=0

69. \_\_\_Are the neighbors mean to you or nice to you? NICE=2; IN-BETWEEN=1; MEAN=0

70. \_\_\_Do you like living in your neighborhood or would you like to live in a different neighborhood? LIKE=2  
(If ELSEWHERE, Ask, "Where would that be?").

IF ANSWER, SCORE=0; IF NO ANSWER, SCORE=1

71. \_\_\_Do your neighbors ignore you (pretend you're not there) or do they talk to you?  
TALK=2; SOMETIMES=1; IGNORE=0

72. \_\_\_Show me how you feel about your neighbors. (Show pictures of faces.)  
HAPPY=2; IN-BETWEEN=1; SAD=0

73. \_\_ Do you feel safe and happy to walk around in your neighborhood near your house, or do you feel afraid to walk around your neighborhood? SAFE/HAPPY=2; NOT=0

Is there anything else that you want to tell me about your neighbors/neighborhood that we haven't already talked about; such as, Things you like?

Things you don't like?

Things you want changed or fixed?

### C. EMPLOYMENT

Do you have a job? (If "YES", Ask about job and then begin with #75. If "NO", Ask #74 and move to next section.)

(Ask only if consumer does not have a job, then skip Employment section if "YES")

74. \_\_ Do you want to have a paid job? NO=2; YES=0

75. \_\_ Do you like your job or do you dislike your job? LIKE=2; IN-BETWEEN=1; DISLIKE=0

76. \_\_ Did you choose to work at \_\_\_\_\_? Y / N (If "YES", Did someone help you with this choice.)

YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0

77. \_\_ Is that a bad place to work or a good place to work? GOOD=2; IN-BETWEEN=1; BAD=0

78. \_\_ Do you like the hours you work? YES=2; IN-BETWEEN=1; NO=0

79. \_\_ Do you work enough hours or do you want to work more hours? ENOUGH=2; MORE=0

80. \_\_ Is the work you do important work or not important work?  
IMPORTANT=2; IN-BETWEEN=1; NOT IMPORTANT=0

81. \_\_ Do you get paid fairly for the work you do? YES=2; IN-BETWEEN=1; NO=0

82. \_\_ Show me how you feel about the money you make from work. (Show pictures of faces.)  
HAPPY=2; IN-BETWEEN=1; SAD=0

83. \_\_ Are the people at work mean to you or are people at work nice to you?  
NICE=2; IN-BETWEEN=1; MEAN=0

84. \_\_ If you had a problem at work or needed help, is there someone at work who helps you or is there no one to help you? SOMEONE=2; NO ONE=0

85. \_\_ Do you have a job coach? Y/N (If "YES", ask follow-up questions. If "NO", mark as 8 "Non Applicable" and go to #86) If "YES", Did you choose (or pick) your job coach (the person who helps you)? Y/N (*If "YES", Did someone help you with this choice?.*)  
YES, WITHOUT HELP=2; YES, WITH HELP=1;  
NO, SOMEONE ELSE CHOSE=0

86. \_\_ Show me how you feel about the people you work with. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0

87. \_\_ Do the people you work with treat you okay, or do they not respect you?  
RESPECT=2; IN-BETWEEN=1; NO RESPECT=0

88. \_\_ Do you have to work all the time or do you get a vacation from work?  
VACATION=2; ALL THE TIME=0

89. \_\_ Show me how you feel about work. (Show pictures of faces.)  
HAPPY=2; IN-BETWEEN=1; SAD=0

90. \_\_ Have you had a lot of different people support you at work?  
NO=2  
(If "YES", Ask "Is that a problem for you?")  
NO=1; YES=0

91. \_\_ Is there something else you would rather do during the day?  
Please list:  
  
NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0

92. \_\_ Do you choose to go to your worksite, or do you have to go?  
CHOOSE=2; SOMETIMES=1; HAVE TO GO=0

Is there anything else that you want to tell me about your job that we haven't already talked about such as; things you like?

Things you don't like?

Things you want changed or fixed?

#### **D. DAYTIME ACTIVITIES - GROUP**

What do you do during the daytime?

(Be clear that you are asking about group daytime activities only, NOT residential free time, and use program or staff names throughout the section so the consumer is clear about exactly what you are asking.)

- 75a. \_\_\_ Do you like your daytime activities at \_\_\_\_\_ or do you dislike them? LIKE=2; DISLIKE=0
- 76a. \_\_\_ Did you choose to go to \_\_\_\_\_? (Did you look at more than one day program?) Y/N  
(If "YES", Did someone help you with this choice?.)  
YES, WITHOUT HELP=2; YES, WITH HELP=1;  
NO, SOMEONE ELSE CHOSE=0
- 77a. \_\_\_ Is that a bad place to go or a good place to go? GOOD=2; IN-BETWEEN=1; BAD=0
- 78a. \_\_\_ Do you like the hours of your day activities? YES=2; IN-BETWEEN=1; NO=0
- 79a. \_\_\_ Do you get enough hours at \_\_\_\_\_ or would you like more hours?  
ENOUGH=2; MORE=0
- 83a. \_\_\_ Are the people you spend time with at \_\_\_\_\_ mean to you or nice to you?  
NICE=2; IN-BETWEEN=1; MEAN=0
- 85a. \_\_\_ Did you choose (or pick) who helps you at \_\_\_\_\_? Y / N  
(If "YES", Did someone help you with this choice?.)  
YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0
- 86a. \_\_\_ Show me how you feel about the people you spend time with during the day at \_\_\_\_\_.  
(Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0
- 87a. \_\_\_ Do the people you spend time with at \_\_\_\_\_ during the day treat you okay, or do they not respect you? RESPECT=2; IN-BETWEEN; NO RESPECT=0
- 89a. \_\_\_ Show me how you feel about your daytime activities at \_\_\_\_\_. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0
- 90a. \_\_\_ Have you had a lot of different people support you during the day?  
NO=2  
(If "YES", Ask "Is that a problem for you?")  
NO=1; YES=0
- 91a. \_\_\_ Is there something else you would rather do during the day?  
Please list:  
  
NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0
- 92a. \_\_\_ Do you choose to go to your daytime activities, or do you have to go?  
CHOOSE=2; SOMETIMES=1; HAVE TO GO=0

#### **E. DAYTIME ACTIVITIES – INDIVIDUAL SUPPORT / COMPANIONSHIP**

Do you have a support person who does things with you? Who is that person? What kinds of things do you do with \_\_\_\_\_?

- 75b. \_\_\_ Do you like your daytime activities or do you dislike them? LIKE=2; DISLIKE=0

- 78b. \_\_\_ Do you like the hours of your day activities? YES=2; IN-BETWEEN=1; NO=0
- 79b. \_\_\_ Do you get enough hours of daytime support with \_\_\_\_\_ or would you like more hours? ENOUGH=2; MORE=0
- 83b. \_\_\_ Are the people you spend time with during the day mean to you or nice to you? NICE=2; IN-BETWEEN=1; MEAN=0
- 85b. \_\_\_ Did you choose (or pick) who helps or supports you during the day?  
Y / N (*If "YES", Did someone help you with this choice?.*)  
YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0
- 86b. \_\_\_ Show me how you feel about the people you spend time with during the day. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0
- 87b. \_\_\_ Do the people you spend time with during the day treat you okay, or do they not respect you? RESPECT=2; IN-BETWEEN=1; NO RESPECT=0
- 89b. \_\_\_ Show me how you feel about what you do with \_\_\_\_\_. (Show pictures of faces.)  
HAPPY=2; IN-BETWEEN=1; SAD=0
- 90b. \_\_\_ Have you had a lot of different people support you during the day?  
NO=2  
(If "YES", Ask "Is that a problem for you?")  
NO=1; YES=0
- 91b. \_\_\_ Is there something else you would rather do during the day?  
Please list:  
  
NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0
- 92b. \_\_\_ Do you choose to go out with \_\_\_\_\_, or do you have to go?  
CHOOSE=2; SOMETIMES=1; HAVE TO GO=0

Is there anything else you want to tell me about your daytime activities that we haven't talked about, such as, things you like?

Things you don't like?

Things you want changed or fixed?

#### **F. VOLUNTEER ACTIVITIES**

What do you do when you volunteer? Do you have a support person who helps you? Y / N  
(Be clear that you are asking about volunteer activities only and use the support person's name or the volunteer job site throughout the section)

75c. \_\_\_ Do you like your volunteer activities or do you dislike them? LIKE=2; DISLIKE=0

76c. \_\_\_ Did you choose to go to (volunteer site)? Y / N (*If "YES", Did someone help you with this*

*choice?.*)

YES, WITHOUT HELP=2; YES, WITH HELP=1;

NO, SOMEONE ELSE CHOSE=0

77c. \_\_\_ Is that a bad place to go or a good place to go? GOOD=2; IN-BETWEEN=1; BAD=0

78c. \_\_\_ Do you like the hours of your volunteer activities? YES=2; IN-BETWEEN=1; NO=0

79c. \_\_\_ Do you get enough hours of volunteer time or would you like more hours?

ENOUGH=2; MORE=0

83c. \_\_\_ Are the people you spend time with when you volunteer mean to you or nice to you?

NICE=2; IN-BETWEEN=1; MEAN=0

85c. \_\_\_ Do you have someone who helps you at your volunteer site? (If "YES", ask follow-up questions. If "NO", go to #86c) Did you choose (or pick) who helps you at

your volunteer site? Y/N (*If "YES", Did someone help you with this choice?.*)

YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0

86c. \_\_\_ Show me how you feel about the people you spend time with when you volunteer.

(Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0

87c. \_\_\_ Do the people you spend time with when you volunteer treat you okay, or do they not respect you? RESPECT=2; IN-BETWEEN=1; NO RESPECT=0

89c. \_\_\_ Show me how you feel about your volunteer activities. (Show pictures of faces.)

HAPPY=2; IN-BETWEEN=1; SAD=0

Is there anything else you want to tell me about your volunteer activities that we haven't talked about, such as, things you like?

Things you don't like?

Things you want changed or fixed?

## G. SOCIAL SUPPORT

### FRIENDS:

Do you have friends that you like to be with? Y / N Who are your friends?

LIST NAMES IN THE CHART BELOW

(If necessary, use the following questions to generate names, list them in the chart below)

*(If she/he asks answers "yes" ask who the friends are and try to determine if they are*

*family, staff, roommates, co-workers, etc.)*

YES, FRIENDS NOT STAFF OR FAMILY=2

YES, FRIENDS WHO ARE STAFF, CARE-GIVERS, OR FAMILY=1

(Repeat #93 for every person listed in the chart below.)

Names	Type	93. Show me how __ usually makes you feel. (Show faces)

94. \_\_ Do you have enough friends or do you wish you had more friends? ENOUGH=2;  
MORE=0

95. \_\_ Do you hardly ever get to see your friends or do you see your friends when you want to see them? If hardly ever, why not or how come you don't see them much?  
(Please indicate below)

*(Try to determine if there are restrictions on when he/she can see friends. Try to factor*

*out situations where the friends are unavailable – this is not the issue.)*

WHENEVER=2; HARDLY EVER=0

96. \_\_ Who do you talk to when you need to talk to someone? SOMEONE=2; NO ONE=0

97. \_\_ Do you have any best friends? (Is there someone you tell personal things to?)  
YES=2; NO=0

98. \_\_ If you need help, who do you ask to help you? SOMEONE=2; NO ONE=0

99. \_\_ Does anyone ask you to help them? SOMEONE=2; NO ONE=0

100.\_\_ On most days, are you usually happy or sad? HAPPY=2; SAD=0

101.\_\_ Are you lonely or do you have plenty of friends? PLENTY=2; LONELY=0

102.\_\_ Do you ever feel lonely, like you don't have anyone to talk to?  
NO=2; SOMETIMES=1; YES=0

FAMILY:

Let's talk about your family members that you don't live with. Do you have family that you see? Who is in your family? (List)

103.\_\_ Do these family members (family members listed above) make you upset or happy?  
HAPPY=2; IN-BETWEEN=1; UPSET=0

104.\_\_ Do you get to see these family members (family members listed above) as much as you want? YES =2; NO=0  
(If "NO", try to determine if there are any restrictions placed on the consumer.)

105.\_\_ Show me how you feel about these family members (family members listed above).  
(Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0

Is there anything else you want to tell me about your friends or family that we haven't already talked about, such as, things you like?

Things you don't like?

Things you want changed or fixed?

## H. ACTIVITIES

What do you do for fun? Can you tell me some things you do for fun?

(Ask the following questions about each activity listed below beginning with those listed by the interviewee. *If the consumer is unable to respond to the "follow-up" questions, please put a check in the appropriate YES/NO column.*)

	YES	NO
<u>Activity</u> Do you ever...	If answer is yes, then alternating the order each time, ask: Do you go (do___) as much as you want or do you hardly ever get to go (do)? AS MUCH AS=2; HARDLY EVER=0	If answer is no, then ask: Do you want to go to (do) ___? NO=2; YES=0
106. go shopping(e.g., groceries, clothing, housewares, CDs)		
107. go out on errands or appointments (e.g., doctor, bank, post office, hair stylist)		
108. go out for exercise (e.g., walking, biking, aerobics, etc.)		
109. play any sports (e.g., bowling, skating, fishing, swimming, playing sports, etc.)		
110. go out for entertainment (e.g., movies, concerts, plays, bars, parties, sporting events)		
111. go out to eat		
112. go to church/synagogue		
113. stay home and do fun things (e.g., watch videos, play cards or games, work on puzzles or craft projects)		
114. visit friends/family		

## **I. GUARDIANSHIP**

Do you have a guardian?

If yes, what is his/her name? (If "no," then go to next section)

115. \_\_\_ Do you get to see or talk to your guardian when you want to? YES=2; SOME=1; NO=0

116. \_\_\_ Did you get to choose (pick) your guardian, or did someone else choose your guardian?  
I CHOSE=2; SOMEONE ELSE CHOSE=0

117. \_\_\_ Show me how you feel about (guardian). (Show pictures of faces)  
HAPPY=2; IN-BETWEEN=1; SAD=0

118. \_\_\_ Does your guardian let you make some decisions for yourself or does she/he make all  
your decisions for you? MAKE OWN DECISIONS=2; GUARDIAN=0

Is there anything else you want to tell me about your guardian that we haven't already talked  
about, such as, things you like?

Things you don't like?

Things you want changed or fixed?

## **J. SERVICE AGENCY**

(Be clear that you are referring to the consumer's case worker and not home provider,  
day service provider, etc. Make sure you are aware of the agency name and of the  
service plan term the consumer is familiar with. Use these names/terms throughout the  
following sections.)

Let's talk about your case manager (service coordinator). Who is your case manager (service  
coordinator)?

119. \_\_\_ Show me how you feel about your case manager (service coordinator). (Show pictures of  
faces) HAPPY=2; IN-BETWEEN=1; SAD=0

120. \_\_ Did you choose (or pick) your case manager? Y / N  
(If "YES", Did someone help you with this choice?.)  
YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0  
Who helped you make this choice?

121. \_\_ Do you get to see your case manager when you want to? YES=2; SOMETIMES=1;  
NO=0

122. \_\_ When you want to talk to (case manager/service coordinator) is it hard or easy to get in  
touch with him/her? EASY=2; IN-BETWEEN=1; HARD=0

123. \_\_ When you ask \_\_\_\_\_ for help, does he/she get you what you need?  
YES=2; SOMETIMES=1; NO=0

124. \_\_ Have you had a lot of different case managers?  
NO=2  
(If "YES", Ask "Is that a problem for you?")  
NO=1; YES=0

Now let's talk about other services.

125. \_\_ Show me how you feel about (your service agency). (Show pictures of faces)  
HAPPY=2; IN-BETWEEN=1; SAD=0

126. \_\_ Did you have a support plan / ISA (IPP) meeting this year? YES=2; NO=0

127. \_\_ When you have your support plan / ISA (IPP) meetings, do people listen to what you  
have to say? LISTEN=2; SOMETIMES=1; DON'T LISTEN=0

128. \_\_ Did you get what you wanted in your support plan / ISA (IPP)? YES=2;  
SOMEWHAT=1; NO=0

129. \_\_ Are the things that are important to you in your support plan / ISA (IPP)?  
YES=2; SOME=1; NO=0

130. \_\_ Do you have a group of friends and family that you count on to help you make  
decisions? (Like the types of support you need, where to live, how to get places?)  
YES=2; NO=0

131. \_\_ Tell me what agency services are available to you at \_\_\_\_\_ (Service agency)?

Please list: \_\_\_\_\_

NAMED=2; COULD NOT NAME=0

132. \_\_\_ Are there other supports and services you wish you had that you don't have now?

Please list: \_\_\_\_\_

NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0

133. \_\_\_ Do you know how much money from (your agency) you have to spend on services? (Do you know how much your budget is?) YES, GIVES FIGURE=2;  
YES, DID NOT GIVE FIGURE=1; NO=0

134. \_\_\_ Do you know how you can use your money/budget from \_\_\_\_\_(service agency) for services?

Please list: \_\_\_\_\_

YES, NAMED=2; YES, BUT DID NOT NAME=1; NO=0

(If Yes to either 133 or 134, then ask question 135, if both questions are no skip 135.)

135. \_\_\_ Who do you ask for help with using your money/budget to get services?

Please list: \_\_\_\_\_

YES, NAMED=2; YES, BUT DID NOT NAME=1; NO=0

136. \_\_\_ Have you ever been told about (your agency's) complaint process or are you not aware of (your agency's) complaint process? TOLD=2; NOT AWARE=0

137. \_\_\_ Have you ever made a formal written complaint to someone at your agency?  
NO=2; YES=0

138. \_\_\_ Have you been told about (your agency's) appeal process or are you not aware of (your agency's) appeal process? TOLD=2; NOT AWARE=0

139. \_\_\_ Do people at (your agency) listen to you or not listen to you?  
LISTEN=2; SOMETIMES=1; NOT LISTEN=0

140. \_\_\_ Do you have trouble changing the things you don't like or do people at (your agency) help change things you don't like?  
HELP CHANGE=2; TROUBLE CHANGING=0

141. \_\_\_ Are you having trouble getting the help you need or are you getting the help you need? (Such as transportation, job coaching, taking a class, taking a vacation, getting medical care, etc.) GET HELP=2; TROUBLE=0

142. \_\_\_ Who would you ask to help you change services or supports you do not like?

Please list:\_\_\_\_\_

NAMED=2; SOMEONE, BUT DID NOT NAME=1; NOBODY NAMED=0

143. \_\_\_ Do you ever get to learn new things (skills)? (Do people help you learn new things?)

Y/N What are they?\_\_\_\_\_

NAMED=2; YES, BUT DID NOT NAME=1; NO=0.

144. \_\_\_ Show me how you feel about the help you get from (your agency).

HAPPY=2; IN-BETWEEN=1; SAD=0

#### **K. HEALTH CARE**

SCORE HAPPY=2; IN-BETWEEN=1; SAD=0 FOR QUESTIONS 145-149 THAT USE FACES (\*).

145. \_\_\_ Do you get to see your doctor when you want/need to? YES=2; NO=0

\*146. \_\_\_ Show me how you feel about the doctor you see when you are sick or when you have checkups. HAPPY=2; IN-BETWEEN=1; SAD=0

147. \_\_\_ Do you get to see your dentist when you want/need to? YES=2; NO=0

\*148. \_\_\_ Show me how you feel about your dentist. HAPPY=2; IN-BETWEEN=1; SAD=0

149. \_\_\_ Are there any other health services that you want/need to have?

Please list:\_\_\_\_\_

NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0

#### **L. VOTING**

150. \_\_\_ Has anyone ever talked to you about voting in elections? YES=2; NO=0.

151. \_\_\_ (*First Ask*) Do you want to vote in elections or do you not want to vote in elections? Y/N

If "NO", then ask, Do you vote in elections? NO=2; YES=0

If "YES", then ask, Do you vote in elections? YES=2; NO=0

## M. SELF-ADVOCACY

Do you know what a self-advocate is? (*Provide an explanation if person is uncertain.*)

(Self-advocacy means speaking up for yourself, telling people what you want, advocating for your rights/what you need?)

152. \_\_\_ Have you gone to a self-advocacy meeting or conference, or have you not been able to go? GONE=2; If "NOT GONE", then ask follow-up question before scoring  
Do you want to go to a self-advocacy meeting, conference, or event? NO=2; YES=0

(If "GONE", then ask #153 and skip to #155)

(If "NOT GONE", then SKIP TO #154)

153. \_\_\_ Why did you go to the self-advocacy meeting, conference, or event? (Check primary reason)

\_\_\_ To get information for self/others  
\_\_\_ To see/meet people – social opportunity  
\_\_\_ To be part of the self-advocacy movement  
\_\_\_ Support  
\_\_\_ Other (please specify) \_\_\_\_\_

154. \_\_\_ Why haven't gone or been able to go? (Check primary reason)

\_\_\_ Not enough time  
\_\_\_ Not interested  
\_\_\_ Can't get a ride  
\_\_\_ Didn't know about it  
\_\_\_ Other (please specify) \_\_\_\_\_

155. \_\_\_ Do you see yourself as being a self-advocate? YES=2; NO=0

156. \_\_\_ Do you want to know more about self-advocacy or do you know enough about it?  
ENOUGH=2; MORE=0.

## N. SELF-DETERMINATION

157. \_\_\_ Do you need to have more control over your life or do you think you have enough control? (Such as control over where you live, what you do during the day, how to spend your money) ENOUGH=2; MORE=0

158. \_\_\_ Are there choices you wish you could make that you don't make now?

Please list: \_\_\_\_\_

NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0

159. \_\_\_ Were you involved in the interviewing and hiring of any of your support staff or were they assigned to you? INVOLVED, NAMED=2; INVOLVED, NOT

NAMED=1

ASSIGNED=0

(If "YES", Ask who.)

160. \_\_\_ Do you need to know more about how to interview and hire your support staff?

NO=2; YES=0

Is there anything else you want to tell me that we haven't talked about already today?



## **APPENDIX B: SELF-PERCEIVED SATISFACTION SCALE, 2001**

### **STATE OF VERMONT (N=253)**

The Vermont Consumer Survey Project is participating in a national Core Indicators Project sponsored by the Board of Directors of the National Association of State Directors of Developmental Disabilities Services. The aim of the project is to establish and validate “core indicators” which would serve as benchmarks against which states could examine and evaluate consumer outcomes for their citizens. The consumer questions that have been included in the national project as key consumer outcomes are indicated in the table of results with asterisks (\*). When national data become available against which to compare local and state results, that information will be included in our reports.

#### **RESIDENTIAL**

- \* 1. Are you happy living there or would you like to live somewhere else?

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SOMEWHERE ELSE</b>
202	16	27

2. Is that a bad place to live or a good place to live?

<b>GOOD</b>	<b>IN-BETWEEN</b>	<b>BAD</b>
168	22	8

- \* 3. Did you have any say in choosing that place to live?

<b>YES</b>	<b>NO</b>
92	94

4. Can you think of a better place to live?

<b>NO</b>	<b>YES, COULD NOT NAME</b>	<b>YES, NAMED PLACE</b>
132	3	52

5. Is the food there pretty bad or do you like the food there?

<b>LIKE</b>	<b>IN BETWEEN</b>	<b>DISLIKE</b>
185	11	4

6. Show me how you feel about the food at your house.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
215	26	7

7. Who decides (picks) what you eat?

<b>SELF</b>	<b>SOMEONE ELSE, LIKE IT</b>	<b>SOMEONE ELSE, DON'T LIKE IT</b>
125	61	11

8. Who decides (picks) what you wear?

<b>SELF</b>	<b>OTHER</b>
179	20

2

\* 9. Do you choose the times you do things each day, like when to get up, when to eat dinner, when to do laundry...?

<b>YES, WITHOUT ASSISTANCE</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO, SOMEONE ELSE CHOOSES</b>
150	34	9

Do you like living with \_\_\_\_ ? (Housemates 1 through 6)

12. Show me how you feel about \_\_\_\_ . (Housemates 1 through 6)

HOUSEMATE	HAPPY	IN-BETWEEN	SAD
1.	59	10	6
2.	48	4	3
3.	50	5	0
4.	28	8	3
5.	15	5	1

*(Ask this question if not living with family)*

\* 13. Did you have any say about who lives there with you?

YES	NO
22	47

Do you like \_\_\_\_ ? (Staff or support people 1 through 4)

16. Point to the face which shows how you feel about \_\_\_\_ .  
(Staff or support people 1 through 4)

STAFF	HAPPY	IN-BETWEEN	SAD
1.	19	2	0
2.	15	1	1
3.	12	0	2
4.	11	1	1

\* 17. Did you have any choice in hiring (did you pick) who works at your house?

YES, SOMEONE NAMED	NO
11	15

18. Have you had a lot of different people support you there?

<b>NO</b>	<b>YES, NOT A PROBLEM</b>	<b>YES, IT HAS BEEN A PROBLEM</b>
8	14	4

For persons living semi-independently with no roommate:

19. Do you like living by yourself?

<b>YES</b>	<b>NO</b>
38	6

20. Would you like to have someone live with you?

<b>NO</b>	<b>YES, FOLLOW UP NOT ANSWERED</b>	<b>YES, FOLLOW UP ANSWERED</b>
27	1	16

21. Show me how you feel about living alone.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
35	4	7

### **THINGS TO DO:**

\* 22. Do you choose or pick the things you do for fun?

<b>YES, UNASSISTED</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO, SOMEONE ELSE CHOOSES</b>
161	27	6

23. Do you have enough to do when you're at home or do you sit around with nothing to do?

<b>ENOUGH</b>	<b>IN-BETWEEN</b>	<b>NOTHING</b>
139	21	32

24. Are you bored when you are at home, or is it fun to be home?

<b>FUN</b>	<b>IN-BETWEEN</b>	<b>BORED</b>
120	35	39

25. Show me how you feel about how you spend your free time at home.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
196	34	13

### **JOBS/CHORES:**

26. Are you told what jobs to do or do you get to pick the jobs/chores you want to do?

<b>PICK</b>	<b>IN-BETWEEN</b>	<b>TOLD</b>
127	17	35

27. Do you have to work too hard there (at home)?

<b>NO</b>	<b>SOMETHINGS</b>	<b>YES</b>
156	12	14

28. Would you like to have more jobs/chores to do?

<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
124	6	50

29. Show me how you feel about the jobs/chores you do around your house.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
173	34	14

### **RULES:**

30. Who makes the rules for living here?

<b>SELF</b>	<b>SOMEONE ELSE</b>
28	67

31. Are the rules for living there good rules or are they bad rules?

<b>GOOD</b>	<b>IN-BETWEEN</b>	<b>BAD</b>
66	11	6

32. What happens if you don't like a rule? Can you change a rule? (like when you have to go to bed etc.)?

<b>COMPROMISE</b>	<b>NOTHING</b>
44	29

33. What if you want to drink a beer or some wine in your house? Is there no drinking allowed there (at home) or can you have a beer or wine there (at home) if you want?

<b>HAVE A DRINK</b>	<b>NO DRINKING ALLOWED</b>	<b>MEDICAL REASONS</b>
133	33	

34. Show me what you think about the rules at your house.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
76	23	12

35. Can you invite your friends or your family over to your house whenever you want to?

<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
155	13	20

36. Who decides when you can have friends/family over to visit?

<b>SELF</b>	<b>OTHER</b>
70	55

**PRIVACY:**

- \* 37. Can you be by yourself as much as you want to? (Do you have enough time to yourself, enough private time?)

<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
161	9	26

38. Does anyone ever open your mail without asking you first?

<b>NO</b>	<b>YES</b>
162	15

- \* 39. Can you use the telephone when you want to?

<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
162	11	16

40. Can you talk on the phone in private or do other people listen in?

<b>PRIVATE</b>	<b>SOMETIMES</b>	<b>LISTEN</b>
145	10	21

- \* 41. When you have friends over, can you be alone with them, or does someone have to be with you?

<b>HAVE PRIVACY</b>	<b>SOMETIMES</b>	<b>NOT ALONE</b>
125	7	38

42. Has anyone ever talked to you about dating? (Having a boyfriend/girlfriend?)

<b>YES</b>	<b>NO</b>
67	108

43. Do you need to know more about dating? (Having a boyfriend/girlfriend?)

<b>NO</b>	<b>YES</b>
117	56

44. Can you have (boyfriend/girlfriend) over to visit whenever you want?

YES	NO
44	11

45. Can (boyfriend/girlfriend) stay overnight at your house if you want, or is (boyfriend/girlfriend) not allowed to stay overnight?

YES, ALLOWED	SOMETIMES	NOT ALLOWED
25	4	22

46. Do other people have to be with you when (boyfriend/girlfriend) is at your house, or can you be alone at you house with (boyfriend/girlfriend) if you want?

NO, CAN BE ALONE	SOMETIMES	YES, OTHER PEOPLE
40	2	10

47. Can you spend time at (boyfriend/girlfriend)'s house whenever you want or are you not allowed to go over to her/his house?

YES	SOMETIMES	NOT ALLOWED
32	4	12

### **MONEY:**

48. Can you have your own money whenever you want it or do you have to ask someone for your money?

HAVE	ASK
104	77

49. Show me how you feel about (self or other) having your money.

HAPPY	IN-BETWEEN	SAD
204	20	15

- \* 50. Can you buy the things you want to buy or does someone else decide how you spend your money?

<b>SELF</b>	<b>SOMEONE ELSE</b>
151	32

51. Do people steal (take) your money?

<b>NO</b>	<b>YES</b>
172	19

**SAFETY:**

52. Do people in your house take your things or do they leave your stuff alone?

<b>LEAVE ALONE</b>	<b>SOMETIMES</b>	<b>TAKE</b>
156	1	11

- \* 53. Do people go into your house without asking?

<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
160	0	27

- \* 54. Does anyone go into your bedroom without asking?

<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
164	7	22

55. Do people go into your house and take your things?

<b>NO</b>	<b>YES, FOLLOW UP NOT ANSWERED</b>	<b>YES, FOLLOW UP ANSWERED</b>
174	4	13

- \* 56. Do you feel safe in your home or do you feel afraid (scared) in your home?

<b>SAFE</b>	<b>IN-BETWEEN</b>	<b>AFRAID</b>
169	13	13

**COMING AND GOING:**

57. Can you go out whenever you want to or do you have to wait for someone to take you?

<b>WHEN WANT</b>	<b>SOMETIMES</b>	<b>WAIT</b>
133	0	56

58. Do you have to wait for someone to bring you home or can you come home when you want to?

<b>WHEN WANT</b>	<b>SOMETIMES</b>	<b>WAIT</b>
149	0	39

59. When people in your house go somewhere, do you have to go or can you stay home alone if you want to?

<b>CAN STAY ALONE</b>	<b>SOMETIMES</b>	<b>HAVE TO GO</b>
95	12	48

60. Do you have a key to your house?

<b>YES</b>	<b>NO</b>
125	65

61. Do you use your key whenever you want to or do you have to ask to use your key?

<b>FREELY</b>	<b>ASK</b>
117	8

**ACCESS/ TRANSPORTATION**

\* 62. When you want to go somewhere, do you have a way to get there?

<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
165	10	15

63. Are there services or supports that you need that you can't get to? (Such as to the doctor, the service agency, to go shopping, to the pharmacy, etc.)

<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
149	2	32

64. Are the places where you go for services or support easy to get to? (e.g., to the doctor, the service agency, to go shopping, to the pharmacy, etc.)

<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
172	0	20

#### **PETS:**

65. Do you like having a pet? (Persons with a pet)

<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
126	5	0

66. Do you want to have a pet? (Persons without a pet)

<b>NO</b>	<b>IN-BETWEEN</b>	<b>YES</b>
38	0	25

67. Can you have a pet in this house if you want to or are no pets allowed? (Persons without a pet)

<b>ALLOWED</b>	<b>IN-BETWEEN</b>	<b>NO PETS ALLOWED</b>
25	0	28

#### **NEIGHBORHOOD**

68. Are the neighbors friendly toward you?

<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
144	14	10

69. Are the neighbors mean to you or are the neighbors nice to you?

NICE	IN-BETWEEN	MEAN
146	15	3

70. Do you like living in your neighborhood or would you like to live in a different neighborhood?

LIKE	DIFFERENT, NOT NAMED	DIFFERENT, NAMED
138	6	28

71. Do your neighbors ignore you (pretend you're not there) or do they talk to you?

TALK	SOMETIMES	IGNORE
123	27	13

72. Show me how you feel about your neighbors.

HAPPY	IN-BETWEEN	SAD
156	29	20

\* 73. Do you feel safe and happy to walk around in your neighborhood near your house, or do you feel afraid to walk around your neighborhood?

SAFE	IN-BETWEEN	NOT SAFE
143	1	26

### **EMPLOYMENT**

74. Do you want to have a paid job?

YES	NO
18	39

75. Do you like your job or do you dislike your job?

LIKE	IN-BETWEEN	DISLIKE
103	10	4

\* 76. Did you choose to work at \_\_\_\_?

<b>YES UNASSISTED</b>	<b>YES WITH ASSISTANCE</b>	<b>SOMEONE ELSE CHOOSES</b>
29	67	18

\* 77. Is that a bad place to work or a good place to work?

<b>GOOD</b>	<b>IN-BETWEEN</b>	<b>BAD</b>
110	4	2

78. Do you like the hours you work?

<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
111	2	5

79. Do you work enough hours or do you want to work more hours?

<b>ENOUGH</b>	<b>MORE</b>
75	43

80. Is the work you do important work or not important work?

<b>IMPORTANT</b>	<b>IN-BETWEEN</b>	<b>NOT IMPORTANT</b>
101	4	7

81. Do you get paid fairly for the work you do?

<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
106	3	6

82. Show me how you feel about the money you make from work.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
121	10	6

\* 83. Are the people at work mean to you or are people at work nice to you?

<b>NICE</b>	<b>IN-BETWEEN</b>	<b>MEAN</b>
106	8	3

84. If you had a problem at work or needed help, is there someone at work who helps you or is there no one to help you?

<b>SOMEONE</b>	<b>SOMETIMES</b>	<b>NO ONE</b>
110	0	9

\* 85. Did you choose (or pick) your job coach (the person who helps you)?

<b>YES, UNASSISTED</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO</b>
13	17	34

86. Show me how you feel about the people you work with.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
112	15	5

87. Do the people you work with treat you okay, or do they not respect you?

<b>RESPECT</b>	<b>IN-BETWEEN</b>	<b>NO RESPECT</b>
101	10	5

88. Do you have to work all the time or do you get a vacation from work?

<b>VACATION</b>	<b>IN-BETWEEN</b>	<b>ALL THE TIME</b>
105	0	9

89. Show me how you feel about work.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
123	7	8

90. Have you had a lot of different people support you at work?

<b>NO</b>	<b>YES, NOT A PROBLEM</b>	<b>YES, IT HAS BEEN A PROBLEM</b>
27	68	14

91. Is there something else you would rather do during the day?

<b>NO</b>	<b>YES, BUT DID NOT NAME</b>	<b>YES, NAMED</b>
92	4	18

92. Do you choose to go to your worksite, or do you have to go?

<b>CHOOSE</b>	<b>SOMETIMES</b>	<b>HAVE TO GO</b>
64	2	46

## **DAYTIME ACTIVITIES- GROUP**

75a. Do you like your daytime activities at \_\_\_\_\_ or do you dislike them?

<b>LIKE</b>	<b>DISLIKE</b>
25	2

76a Did you choose to go to \_\_\_\_\_?

<b>YES, UNASSISTED</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO, SOMEONE ELSE CHOOSES</b>
7	9	6

\* 77a. Is that a bad place to go or a good place to go?

<b>GOOD</b>	<b>IN-BETWEEN</b>	<b>BAD</b>
24	0	2

78a. Do you like the hours of your day activities?

<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
25	0	1

\* 79a. Do you get enough hours of daytime support or would you like more hours?

<b>ENOUGH</b>	<b>IN-BETWEEN</b>	<b>MORE</b>
18	0	8

83a. Are people you spend time with during the day mean to you or nice to you?

<b>NICE</b>	<b>IN-BETWEEN</b>	<b>MEAN</b>
22	2	2

\* 85a. Did you choose (or pick) who helps you at your day program site?

<b>YES, UNASSISTED</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO, SOMEONE ELSE CHOOSES</b>
7	7	7

86a. Show me how you feel about the people you spend time with during the day.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
35	1	0

87a. Do the people you spend time with during the day treat you okay, or do they not respect you?

<b>RESPECT</b>	<b>IN-BETWEEN</b>	<b>NO RESPECT</b>
21	1	1

89a. Show me how you feel about your daytime activities.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
31	3	1

90a. Have you had a lot of different people support you at your day program?

<b>NO</b>	<b>YES, NOT A PROBLEM</b>	<b>YES, IT HAS BEEN A PROBLEM</b>
3	18	3

91a. Is there something else you would rather do during the day?

<b>NO</b>	<b>YES, BUT DID NOT NAME</b>	<b>YES, NAMED</b>
19	2	4

92a. Do you choose to go to your daytime activities, or do you have to go?

<b>CHOOSE</b>	<b>SOMETIMES</b>	<b>HAVE TO GO</b>
12	0	8

## **DAY ACTIVITIES-INDIVIDUAL**

75b. Do you like your daytime activities or do you dislike them?

<b>LIKE</b>	<b>DISLIKE</b>
63	3

78b. Do you like the hours of your day activities?

<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
60	1	3

79b. Do you get enough hours of daytime support with \_\_\_\_\_ or would you like more hours?

<b>ENOUGH</b>	<b>MORE</b>
41	24

83b.Are the people you spend time with during the day mean to you or nice to you?

<b>NICE</b>	<b>IN-BETWEEN</b>	<b>MEAN</b>
62	4	0

85b.Did you choose (or pick) who helps or supports you during the day?

<b>YES, UNASSISTED</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO, SOMEONE ELSE CHOOSES</b>
16	18	30

86b.Show me how you feel about the people you spend time with during the day?

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
83	9	3

87b.Do the people you spend time with during the day treat you okay, or do they not respect you?

<b>RESPECT</b>	<b>IN-BETWEEN</b>	<b>NO RESPECT</b>
59	4	3

89b.Show me how you feel about what you do with \_\_\_\_\_.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
85	8	3

90b.Have you had a lot of different people support you during the day?

<b>NO</b>	<b>YES, NO PROBLEM</b>	<b>YES, IT IS A PROBLEM</b>
24	27	9

91b.Is there something else you would rather do during the day?

<b>NO</b>	<b>YES, NOT NAMED</b>	<b>YES, NAMED</b>
49	1	14

92b. Do you choose to go out with \_\_\_\_\_, or do you have to go?

<b>CHOOSE</b>	<b>SOMETIMES</b>	<b>HAVE TO GO</b>
36	4	23

## **VOLUNTEER ACTIVITIES**

75c. Do you like your volunteer activities or do you dislike them?

<b>LIKE</b>	<b>DISLIKE</b>
31	3

76c. Did you choose to go to \_\_\_\_\_?

<b>YES, UNASSISTED</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO, SOMEONE ELSE CHOOSES</b>
17	10	8

77c. Is that a bad place to go or a good place to go?

<b>GOOD</b>	<b>IN-BETWEEN</b>	<b>BAD</b>
32	0	3

78c. Do you like the hours of your volunteer activities?

<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
33	1	0

1

79c. Do you get enough hours of volunteer time or would you like more hours?

<b>ENOUGH</b>	<b>IN-BETWEEN</b>	<b>MORE</b>
22	0	12

83c. Are people you spend time with when you volunteer mean to you or nice to you?

<b>NICE</b>	<b>IN-BETWEEN</b>	<b>MEAN</b>
32	1	0

85c. Did you choose (or pick) who helps you at your volunteer site?

<b>YES, UNASSISTED</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO, SOMEONE ELSE CHOOSES</b>
10	7	9

86c. Show me how you feel about the people you spend time with when you volunteer.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
36	4	3

87c. Do the people you spend time with when you volunteer treat you okay, or do they not respect you?

<b>RESPECT</b>	<b>IN-BETWEEN</b>	<b>NO RESPECT</b>
30	3	2

89c. Show me how you feel about your volunteer activities.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
41	1	1

## **FRIENDS and SOCIAL SUPPORT**

Do you have friends you like to be with?

\*93. Show me how Friend's name usually makes you feel. (Friends 1-5)

<b>FRIENDS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
1	183	10	4
2	137	20	1
3	93	13	2
4	62	4	1
5	29	2	1

94. Do you have enough friends or do you wish you had more friends?

<b>ENOUGH</b>	<b>IN-BETWEEN</b>	<b>MORE</b>
109	0	72

- \* 95. Do you hardly ever get to see your friends, or do you see your friends when you want to see them?

<b>WHENEVER</b>	<b>SOMETIMES</b>	<b>HARDLY EVER</b>
144	2	23

96. Who do you talk to when you need to talk to someone?

<b>SOMEONE NAMED</b>	<b>NO ONE</b>
171	8

- \* 97. Do you have any best friends? (Is there someone you tell personal things too?)

<b>SOMEONE NAMED</b>	<b>NO ONE</b>
130	49

98. If you need help, who do you ask to help you?

<b>SOMEONE NAMED</b>	<b>SOMEONE, NO NAME</b>	<b>NO ONE</b>
173	0	6

99. Does anyone ask you to help them?

<b>SOMEONE NAMED</b>	<b>SOMEONE, NO NAME</b>	<b>NO ONE</b>
117	1	69

100. On most days, are you usually happy or sad?

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
148	5	35

101. Are you lonely or do you have plenty of friends?

<b>PLENTY</b>	<b>IN-BETWEEN</b>	<b>LONELY</b>
136	3	45

\*102.Do you ever feel lonely, like you don't have anyone to talk to?

<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
104	38	43

## **FAMILY**

103.Does your family make you upset or happy?

<b>HAPPY</b>	<b>IN BETWEEN</b>	<b>UPSET</b>
126	19	12

\* 104.Do you get to see your family as much as you want?

<b>YES</b>	<b>IN BETWEEN</b>	<b>NO</b>
112	0	46

105.Show me how you feel about your family.

<b>HAPPY</b>	<b>IN BETWEEN</b>	<b>SAD</b>
167	21	9

## **ACTIVITIES**

What do you do for fun? Can you tell me some things you do for fun?

<u>Activity</u> Do you ever...	If answer is yes, then alternating the order each time, ask: Do you go/do as much as you want or do you hardly ever get to go?		If answer is no, then ask: Do you want to go to ___?	
	AS MUCH AS=2	HARDLY EVER=0	NO=2	YES=0
*106. go shopping	136	39	8	2
*107. go out on errands or appointments	133	33	13	3
*108. go out for exercise	132	32	12	11
*109. play any sports	92	32	42	22
110. go out for entertainment	84	49	27	23
*111. go out to eat	128	40	6	12
*112. go to church/synagogue	61	13	75	34
113. stay home and do fun things	150	25	6	3
114. visit friends/family	121	43	10	9

## **GUARDIANSHIP:**

115. Do you get to see or talk to your guardian when you want to? (Persons with guardianship)

<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
71	8	8

116. Did you get to choose (pick) your guardian, or did someone else choose your guardian?

<b>CHOSE</b>	<b>IN-BETWEEN</b>	<b>SOMEONE ELSE CHOSE</b>
42	0	49

117.Show me how you feel about (guardian).

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
115	17	12

118.Does your guardian let you make some decisions for yourself or does she/he make all your decisions for you?

<b>OWN DECISIONS</b>	<b>GUARDIAN</b>
63	31

**SERVICE AGENCY:**

119.Show me how you feel about your caseworker.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
194	18	7

\* 120.Did you choose (or pick) your caseworker?

<b>YES, UNASSISTED</b>	<b>YES, WITH ASSISTANCE</b>	<b>NO, SOMEONE ELSE CHOOSES</b>
37	30	99

121.Do you get to see your caseworker when you want to?

<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
121	26	23

122.When you want to talk to (case worker) is it easy or hard to get in touch with him/her?

<b>EASY</b>	<b>IN-BETWEEN</b>	<b>HARD</b>
104	31	32

\* 123. When you ask \_\_\_\_\_ for help, does he/she get you what you need?

<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
146	16	5

124. Have you had a lot of different case managers?

<b>NO</b>	<b>YES, NO PROBLEM</b>	<b>YES, IT IS A PROBLEM</b>
80	59	30

125. Show me how you feel about (your service agency).

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
190	29	13

126. Did you have a service plan meeting this year?

<b>YES</b>	<b>NO</b>
127	29

127. When you have your ISA (IPP/ISP) meetings, do people listen to what you have to say?

<b>LISTEN</b>	<b>SOMETIMES</b>	<b>DON'T LISTEN</b>
145	10	6

128. Did you get what you wanted in your ISA (IPP/ISP)?

<b>YES</b>	<b>SOMEWHAT</b>	<b>NO</b>
127	15	13

129. Are the things that are important to you in your ISA (IPP/ISP)?

<b>YES</b>	<b>SOMEWHAT</b>	<b>NO</b>
133	10	12

130. Do you have a group of friends and family that you count on to help you make decisions?

<b>YES</b>	<b>NO</b>
142	34

131. Tell me what agency services are available to you?

<b>NAMED</b>	<b>COULD NOT NAME</b>
86	80

132. Are there other supports and services you wish you had that you don't have now?

<b>NO</b>	<b>YES, BUT DID NOT NAME</b>	<b>YES, NAMED</b>
137	4	21

133. Do you know how much money from (your agency) you have to spend on services? (Do you know how much your budget is?)

<b>YES, GIVES FIGURE</b>	<b>YES, DID NOT GIVE FIGURE</b>	<b>NO</b>
17	11	137

134. Do you know how you can use your money/budget for services?

<b>YES, NAMED</b>	<b>YES, BUT DID NOT NAME</b>	<b>NO</b>
27	9	126

135. Who do you ask for help with using your money/budget to get services?

<b>YES, NAMED</b>	<b>YES, BUT DID NOT NAME</b>	<b>NO</b>
133	1	22

136. Have you ever been told about (your agency's) complaint process or are you not aware of (your agency's) complaint process

<b>TOLD</b>	<b>NOT AWARE</b>
35	136

137. Have you ever made a formal written complaint to someone at your agency?

<b>NO</b>	<b>YES</b>
148	25

138. Have you been told about (your agency's) appeal process or are you not aware of (your agency's) appeal process?

<b>TOLD</b>	<b>NOT AWARE</b>
28	148

139. Do people at (your agency) listen to you or not listen to you?

<b>LISTEN</b>	<b>SOMETIMES</b>	<b>NOT LISTEN</b>
149	21	11

140. Do you have trouble changing the things you don't like or do people at (your agency) help change things you don't like?

<b>HELP CHANGE</b>	<b>TROUBLE CHANGING</b>
140	24

141. Are you having trouble getting the help you need or are you getting the help you need?

<b>GET HELP</b>	<b>TROUBLE</b>
161	16

142. Who would you ask to help you change services or supports you do not like?

<b>NAMED</b>	<b>SOMEONE, BUT DID NOT NAME</b>	<b>NOBODY NAMED</b>
135	2	23

143. Do you ever get to learn new things (skills)? (Do people help you learn new things?) Y/N What are they? \_\_\_\_\_

<b>NAMED</b>	<b>YES, BUT DID NOT NAME</b>	<b>NO</b>
73	31	67

144. Show me how you feel about the help you get from (your agency).

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
193	23	15

#### **HEALTH CARE:**

145. Do you get to see your doctor when you want to?

<b>YES</b>	<b>NO</b>
173	10

146. Show me how you feel about the doctor you see when you are sick or when you have checkups.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
194	24	10

147. Do you get to see your dentist when you want/need to?

<b>YES</b>	<b>NO</b>
163	12

148. Show me how you feel about your dentist.

<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
172	28	17

149.Are there any other health services that you would like to have?

<b>NO</b>	<b>YES, NOT NAMED</b>	<b>YES, NAMED</b>
155	4	6

## **VOTING**

150.Has anyone ever talked to you about voting in elections?

<b>YES</b>	<b>NO</b>
100	77

151.*(First Ask)* Do you want to vote in elections or do you not want to vote in elections?

If “NO”, then ask, Do you vote in elections?

If “YES”, then ask, Do you vote in elections?

<b>YES</b>	<b>NO</b>
154	23

## **SELF-ADVOCACY**

\*152. Have you gone to a self-advocacy meeting or conference, or have you not been able to go)?

<b>GONE</b>	<b>NOT GONE</b>
53	109

153.Why did you go to the self-advocacy meeting, conference, or event? (Check primary reason)

<b>INFORMATION</b>	<b>SOCIAL OPPORTUNITY</b>	<b>PART OF SELF ADVOCACY MOVEMENT</b>	<b>OTHER</b>
0	53	0	0

153. Why haven't you gone or been able to go? (Check primary reason)

<b>NOT ENOUGH TIME</b>	<b>NOT INTERESTED</b>	<b>NO RIDE</b>	<b>DID NOT KNOW ABOUT IT</b>	<b>OTHER</b>
0	95	0	1	0

155. Do you see yourself as being a self-advocate?

<b>YES</b>	<b>NO</b>
132	33

156. Do you want to know more about self-advocacy or do you know enough about it?

<b>ENOUGH</b>	<b>MORE</b>
86	79

## **SELF-DETERMINATION**

157. Do you need to have more control over your life or do you think you have enough control?

<b>ENOUGH</b>	<b>MORE</b>
146	31

158. Are there choices you wish you could make that you don't make now?

<b>YES, NAMED</b>	<b>YES, NOT NAMED</b>	<b>NO</b>
121	12	36

159. Were you involved in the interviewing and hiring of any of your support staff or were they assigned to you?

<b>INVOLVED</b>	<b>ASSIGNED</b>
36	113

160. Do you need to know more about how to interview and hire your support staff?

<b>NO</b>	<b>YES</b>
96	52

## APPENDIX C:

### **Factors Included in Each Subscale Based on 2001 Survey (2001)**

From the Self-Perceived Satisfaction Scale:

- RESIDENTIAL SATISFACTION – Includes the following questions:  
q1,q2,q4,q5,q6, mean of q10-q12, mean of q14-q16,  
q18,q19,q20,q21,q23,q24,q25,q27,q28,q29,q31,q34,q65,q67,q49,q51,q52,q53,q54,q55,  
q56,q62,q63,q64,q65,q66

- RESIDENTIAL AUTONOMY – Includes the following questions:  
q3,q7,q8,q9,q13,q17,q22,q26,q30,q32,q33,q35,q36,q37,q38,q39,q40,q41,  
q44,q45,q46,q47,q48,q50,q57,q58,q59,q60,q61,q67

NEIGHBOR SATISFACTION – Includes Neighborhood questions q68- q73

- WORK SATISFACTION – Includes Employment questions  
(q75,q76,q77,q78,q79,q80,q81,q82,q83,q84, q86,q87,q88,q89).

DAY PROGRAM SATISFACTION – Includes Daytime Activities questions  
(q75a,q76a,q77a,q78a,q79a,q83a,q86a,q87a,q89a,q75b,q78b,q79b,q83b,  
q86b,q87b,q89b,q75c,q76c,q77c,q79c,q83c, q86c,q87c,q89c).

- SOCIAL SUPPORT SATISFACTION – Includes Friends, Social Support, and Family questions (mean of  
q93,q94,q95,q96,q97,q98,q99,q100,q101,q102,q103,q104,q105)
- Activities and Opportunities SATISFACTION – Questions (q106-q114).
- GUARDIAN SATISFACTION – Includes all Guardianship questions (q115, q116, q117, q118).
- Service Satisfaction – Includes questions  
(q119,q120,q121,q122,q123,q124,q125,q126,q127,q128,q129,q130,  
q139,q140,q141,q142,q143,q144).
- HEALTH SATISFACTION – (q145,q146,q147,q148,q149).
- *Additional questions for the full self-report have been added since the 1997 interview in accordance with the Federal Core Indicators Project, and at the request of the Division of Developmental Services. These questions are not included in the subscales, so that comparisons can be made across years. However, response to these questions and all other questions can be found in Appendix B.*

## APPENDIX D:

### **Satisfaction and Type of Developmental Home (STATE 2001)**

During the summer of 2001 interview sessions, consumers living in Development Homes were divided into Developmental Homes with Families and Developmental Homes with Paid Roommates. To determine if the type of Developmental Home living situation made a significant difference in satisfaction across the state, t-test comparisons for satisfaction subscales were made between consumers living in Developmental Homes with a Family and consumers living in Developmental Homes with a Paid Roommate. There were no differences in satisfaction on any subscale except Neighborhood satisfaction. Since the two Developmental Home living situations were similar in all other outcomes for the 2001 survey they were combined for further analyses at the agency level.

### **Subscales and Total Satisfaction By Developmental Home Residential Type** (STATE 2001)

Reported as Average Percent Satisfied or Percent Positive

Subscale	DH Roommate	DH Family	Mean For All Persons
Number People	15	72	87
Residential	91	86	87
Autonomy	70	61	63
* Neighborhood	99	85	87
Work	64	61	62
Day Program	86	84	84
Social Support	85	81	81
Activities	71	78	77
Guardianship	73	78	77
Services	81	78	78
Health	96	93	94

*Note: \* indicates a significant difference for the given subscale ( $p < .05$ ).*

### **Appendix E - Consumers scheduling by Agency**

	Full Interview	Picture Only Interview	Unable to complete interview	Person's choice	Person out of town	Person incapacitated	Agency decision (Communication Issue)	Agency scheduling oversight	Guardian's decision	Reason unknown	Other	Total
CVS	21	3	1	0	0	0	11	0	0	0	0	36
CA	39	7	12	8	0	1	10	0	0	0	4	81
HCS	26	4	2	1	0	0	45	0	0	0	0	78
NKHS	58	27	8	1	1	0	13	3	2	1	4	118
SCC	10	0	2	0	0	0	1	0	0	0	0	13
UCS	47	11	5	0	3	0	17	0	0	0	1	84
Total	201	52	30	10	4	1	97	3	2	1	9	410